

# Increasing access to integrated ESKD care as part of universal health coverage



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**The global nephrology community recognizes the need for a cohesive strategy to address the growing problem of end-stage kidney disease (ESKD). In March 2018, the International Society of Nephrology hosted a summit on**

**integrated ESKD care, including 92 individuals from around the globe with diverse expertise and professional backgrounds. The attendees were from 41 countries, including 16 participants from 11 low- and lower-middle-income countries. The purpose was to develop a strategic plan to improve worldwide access to integrated ESKD care, by identifying and prioritizing key activities across 8 themes: (i) estimates of ESKD burden and treatment coverage, (ii) advocacy, (iii) education and training/workforce, (iv) financing/funding models, (v) ethics, (vi) dialysis, (vii) transplantation, and (viii) conservative care. Action plans with prioritized lists of goals, activities, and key deliverables, and an overarching performance framework were developed for each theme. Examples of these key deliverables include improved data availability, integration of core registry measures and analysis to inform**

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development of health care policy; a framework for advocacy; improved and continued stakeholder engagement; improved workforce training; equitable, efficient, and cost-effective funding models; greater understanding and greater application of ethical principles in practice and policy; definition and application of standards for safe and sustainable dialysis treatment and a set of measurable quality parameters; and integration of dialysis, transplantation, and comprehensive conservative care as ESKD treatment options within the context of overall health priorities. Intended users of the action plans include clinicians, patients and their families, scientists, industry partners, government decision makers, and advocacy organizations. Implementation of this integrated and comprehensive plan is intended to improve quality and access to care and thereby reduce serious health-related suffering of adults and children affected by ESKD worldwide.

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KEYWORDS: advocacy; conservative care; dialysis; end-stage kidney disease; ESKD; funding; training; transplantation; universal health coverage

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**K**idney disease is recognized as a global public health problem, a risk multiplier for many other conditions, and for its association with cardiovascular disease (CVD), diabetes, and infections. Chronic kidney disease (CKD) progresses to end-stage kidney disease (ESKD), which requires kidney replacement therapy (KRT; dialysis or kidney transplant) or comprehensive conservative care (nondialytic care) (Table 1 and Figure 1). The prevalence of KRT for ESKD is rising worldwide, and the fastest growth is occurring in low-income countries (LICs) and lower-middle-income countries (LMICs).<sup>1</sup>

Soon after it became clear that dialysis could be performed as a chronic therapy in the 1960s, insufficient funding emerged as the major barrier to accessing treatment. The presumption that funding for dialysis would allow relatively young, employed, taxpaying members of society with ESKD to be rehabilitated and return to work led to a public debate in the US that culminated in passage of the Social Security Amendment by Congress in 1972.<sup>2</sup> Removal of financial barriers laid the foundation for rapid expansion of dialysis programs in the US and later in the rest of the developed world—to the extent that access to dialysis is now used globally as a benchmark for societal willingness to pay for medical care.<sup>3</sup>

As the magnitude of ESKD burden became apparent, with its financial consequences to the health system, the need to prioritize prevention was realized<sup>4,5</sup> (Figure 1). Directing resources to prevention of CKD and ESKD rather than provision of ESKD care is much more cost-effective. However, even optimal prevention and treatment of kidney disease will not obviate the need for KRT. It is estimated that in 2010, 2.62 million people were receiving KRT worldwide for ESKD, and

that a further 2.3 to 7.1 million, mainly in LMICs, required KRT but died for want of it.<sup>1</sup> Dialysis, in particular hemodialysis (HD), is commonly considered to be the default treatment for ESKD, but not all patients are suitable candidates or will benefit from it. Furthermore, several large registry studies and systematic reviews have confirmed that in appropriate patients, transplantation provides survival advantage and better quality of life, and is more cost-effective than dialysis.<sup>6–9</sup> Hence, in the absence of resource constraints, ESKD care should ideally be available as an integrated mix of peritoneal dialysis (PD), HD, transplantation, and conservative care (nondialytic care), and patients should be able to choose and transition between the different modalities (Figure 1). Non-resource determinants of choice of modality for ESKD care include age, comorbidity, life expectancy, and lifestyle considerations. For suitable candidates, kidney transplant is the best form of KRT, and among the rest, a significant proportion are best treated with conservative care. In 2015, 84,347 kidney transplants were performed worldwide (1950 were pediatric; i.e., patients < 15 years old), representing an increase of 5.5% over 2014.<sup>10</sup> However, the number of transplants falls far short of the current global demand.

Health care professionals and administrators must balance their responsibilities to the health care system with those to

**Table 1 | Definitions of ESKD, supportive care, and comprehensive conservative care**

#### ESKD

- The last stage of CKD and when KRT (hemodialysis, peritoneal dialysis, or kidney transplant) could be considered to improve longevity or quality of life.

#### Supportive care

- Involves services aimed at improving the HRQoL of patients with established CKD.
- Based on the principles of palliative care, which is defined by the World Health Organization as an approach that improves the HRQoL of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems.

#### Conservative care

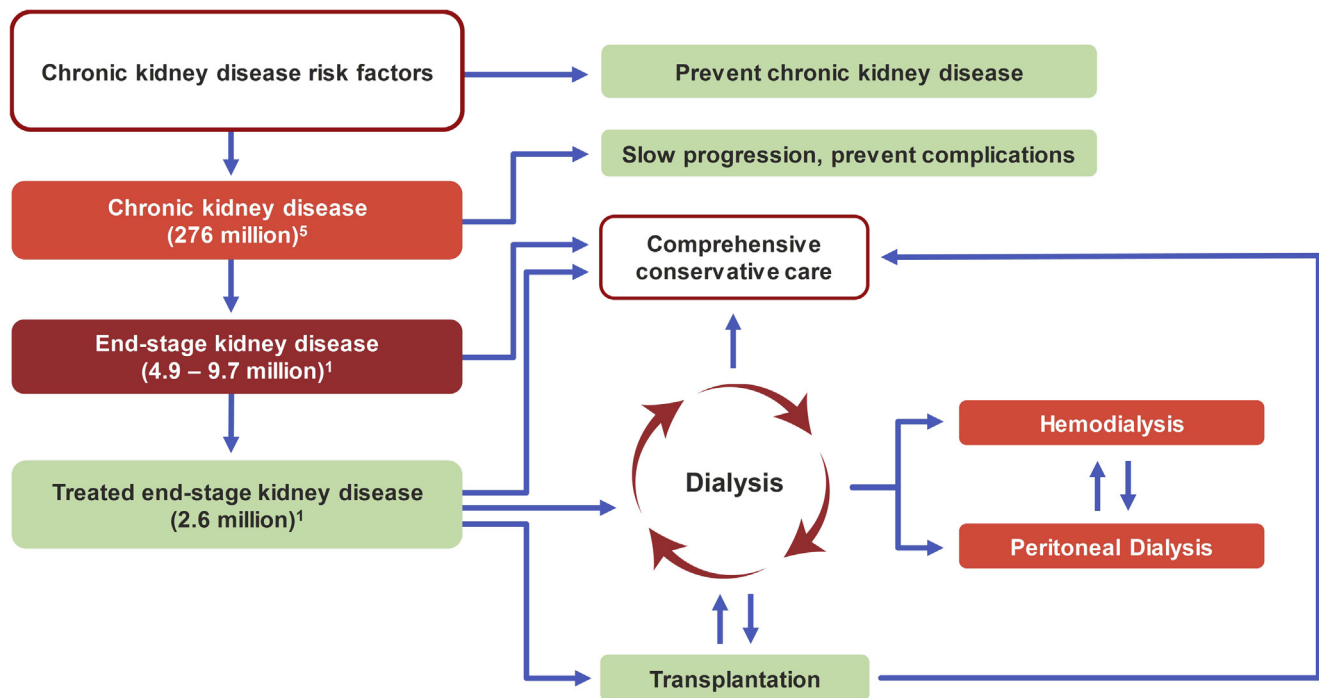
- Can be an alternative to KRT and delivered in 1 of 2 settings:
  - As “comprehensive conservative care,” where conservative care is either chosen or medically advised. This is planned, holistic, person-centered care that includes the following:
    - Interventions to delay progression of kidney disease and minimize risk of adverse events or complications
    - Shared decision making
    - Active symptom management
    - Detailed communication including advance care planning
    - Psychological support
    - Social and family support
    - Cultural and spiritual domains of care

Of note, comprehensive conservative care does not include dialysis.

- As “choice-restricted conservative care,” where resource constraints have prevented or limited access to KRT and, therefore, while not chosen, conservative care is preferable to no care at all.

CKD, chronic kidney disease; ESKD, end-stage kidney disease; HRQoL, health-related quality of life; KRT, kidney replacement therapy.

Modified from Davison SN, Levin A, Moss AH, et al. Kidney Disease: Improving Global Outcomes. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int.* 2015;88:447–459.<sup>11</sup>



**Figure 1 | End-stage kidney disease pathways.**

the individual patient. In LMICs with limited resources, prioritization of KRT must be balanced against other pressing societal needs such as sanitation, clean water, prevention and treatment of infectious diseases and noncommunicable diseases (NCDs; including diabetes, hypertension, CVD, and CKD itself), and reproductive and pediatric health. Thus, how ESKD care is provided for individual patients will be decided based not only on their health condition, their family, and their social and financial resources, but also by the health care setting in which they receive care.

### Brief methods

In view of the need for a cohesive plan to address the challenge of ESKD, especially in emerging economies, the International Society of Nephrology (ISN) organized a summit in Sharjah, United Arab Emirates, in March 2018. The summit was co-chaired by Drs. Simon Davies, Fred Finkelstein, David Harris, and Vivekanand Jha, and participants from around the globe included 92 individuals with diverse expertise (administrators, clinicians, clinical and translational researchers, epidemiologists, industry scientists, nurses, nurse practitioners, pediatric nephrologists, an ethicist, a health economist, a patient, and a representative from the World Health Organization [WHO]). The attendees were from 41 countries, including 16 from 11 LICs and LMICs. The purpose of the meeting was to develop a roadmap to improve worldwide access to integrated ESKD care. Steps in achieving this goal include understanding current global differences in ESKD care; considering ethical, technological, human resource, financial, and cultural issues involved in the expansion of ESKD care; and supporting development of all aspects of just and equitable ESKD care provision in LMICs. The meeting

provided opportunities to define and design concrete strategies to fill gaps in knowledge and practice, and to create a performance framework to evaluate progress over time.

Participants met for 2.5 days to develop the plan, which was based on 8 themes predefined by the 4 co-chairs (Table 2), under the overarching domains of advocacy, sustainability, equity, and integration. All delegates participated in 2 of 8 working groups, each of which addressed a single area of focus. Pre-work for the meeting consisted of identification of key issues, supporting literature searches, and facilitated discussion. Using an iterative process, each group produced a prioritized list of key issues, goals, activities, and deliverables.

The themes and areas of focus are discussed in the following sections, noting the gaps in knowledge and practice, and listing activities recommended to address the gaps. The performance framework is designed to track activity progress over time. Recognizing the diversity of health care systems in LMICs, the participants emphasized the need to individualize and tailor the implementation of proposed action steps according to local needs, culture, geopolitical climate, and available resources. Participants also stressed the value of sharing experiences in platforms such as the summit to evaluate progress and make course corrections. Participants agreed that what is important for the patient would be a key determinant of any such plan.

### Theme 1: estimates of ESKD burden and treatment coverage. Explain the reasons for and monitor global differences in the incidence and prevalence of ESKD, ESKD care, and modality of ESKD care

Known KRT prevalence varies more than 1000-fold across the globe from close to zero per million population (pmp) in

parts of the Pacific Islands and Africa (e.g. Rwanda 2.8 pmp) to over 2000 pmp in parts of North and East Asia (e.g., 3317 pmp in Taiwan and 2529 pmp in Japan), suggesting large inequities in global access to KRT.<sup>12–14</sup> Four-fifths of all patients with ESKD treated with KRT reside in North America, Japan, or Europe.<sup>12,15,16</sup>

Inequities are also evident in the relative availability of different forms of KRT (Figure 2 and Supplementary Tables S1 and S2). For example, PD, useful for adults but particularly appropriate for children, is available in only 29% of LICs.<sup>13,14</sup> HD services may vary in different regions of the same country and also between rural and urban areas. The quality of delivered dialysis varies widely, as will be discussed below, but its assessment is difficult and unreliable. Kidney transplantation, which for suitable candidates provides the best survival, quality of life, and is most cost-effective,<sup>17</sup> is available in only 36% of African countries and worldwide in only 12% of LICs.<sup>13,14</sup> In those that do provide kidney transplantation, rates vary from <1 pmp in Bangladesh to 71 pmp in the Mexican state of Jalisco.<sup>12</sup> There are significant differences in transplantation rates even within countries falling in the same income category. Living donor transplantation is the most common type of transplantation available in LMICs.

Socioeconomic factors are the major drivers of the observed differences in the epidemiology of ESKD, in particular ESKD care. KRT prevalence is highly correlated with national wealth<sup>1,16</sup> (Figure 2 and Supplementary Tables S1 and S2). Approximately 93% of individuals receiving KRT in 2010 resided in high-income countries (HICs) or upper-middle-income countries (UMICs), such that there was a 70-fold greater prevalence in the rates of KRT in these countries compared with their LMIC counterparts.<sup>1,18,19</sup> The most important barrier to KRT in LICs and LMICs is the high cost, which the patients have to pay from their own resources. The annual costs of dialysis have been reported to be 7- to 48-fold higher than average annual incomes.<sup>20</sup> The high cost leads to premature withdrawal of KRT, premature death, and severe financial debt for surviving family members, particularly in LICs.<sup>21,22</sup>

Other factors influencing the epidemiology of ESKD care are summarized in Figure 3. Patient characteristics, such as female gender, older age, indigenous racial origin,

socioeconomic status, poor health literacy, and high burden of comorbidities have all been associated with reduced access to and/or use of KRT.<sup>12,23–25</sup> In most African and South and Southeast Asian countries, children's access to dialysis is severely restricted.<sup>25,26</sup> Even among and within HICs, there are wide variations in the incidence and prevalence of ESKD treated with KRT not explained by differences in national income and in part related to the cause and severity of disease and age of the patients.<sup>1,27</sup>

The highly variable availability, coverage, and quality of ESKD registries prevent proper understanding of the epidemiology of ESKD and ESKD care around the world. This is particularly true in LICs, where nondialysis CKD, dialysis, and kidney transplant registries are available in only 6%, 18%, and 0% of countries, respectively.<sup>13,14,28</sup> African (35%) and South Asian (40%) countries have the lowest frequencies of dialysis registries and are also the areas where the gaps between treated and untreated ESKD are highest.<sup>13,14</sup> Similarly, only 19% of African countries and 40% of South Asian countries have a transplant registry.<sup>13,14</sup> Strategies to address this gap are discussed below and summarized in Table 3.

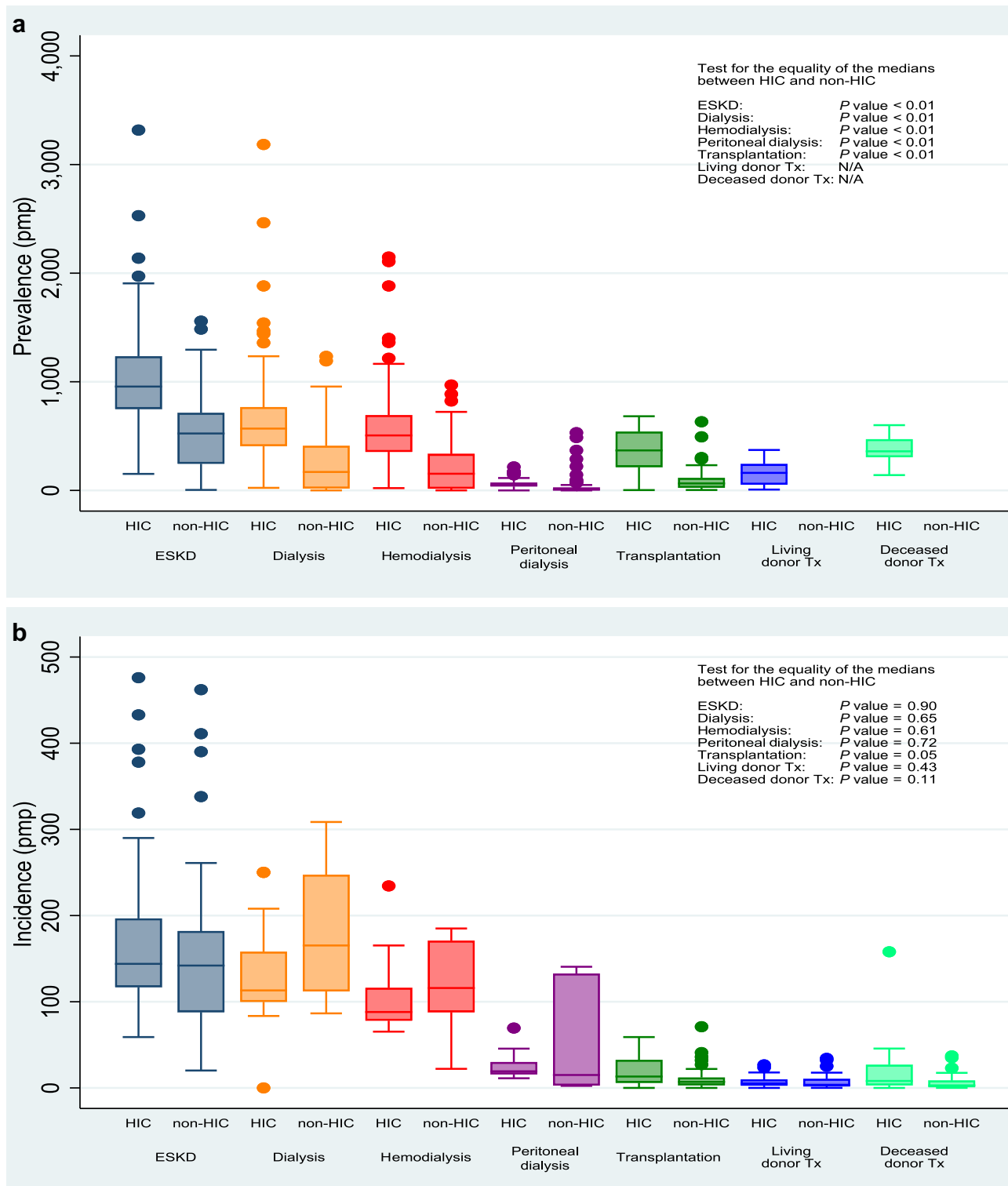
**Improve estimates of the incidence and prevalence of ESKD and ESKD care, including capturing KRT modality and outcomes.** A cornerstone of understanding the global ESKD treatment gap is establishing robust health information systems in each country as a means to define CKD and ESKD burdens, guide resource allocation to areas of need, identify barriers to accessing KRT, capture costs of treatment, and monitor KRT health outcomes, thereby informing KRT service planning and enabling policy development (including CKD prevention and control). A number of LMICs are in the process of setting up national dialysis registries; the ISN is supporting these efforts through the Share-RR project (<https://www.theisn.org/advocacy/share-rr>), which will develop a resource that supports establishment of a renal registry to support advocacy, quality assurance, and research. This project will facilitate sharing of a data dictionary, registry policies, procedures, governance structures, databases, data sets, technology platforms, files, and consent processes. Surveys of existing registries will inform the establishment of a minimum data set to permit benchmarking between registries

**Table 2 | ESKD summit themes and areas of focus**

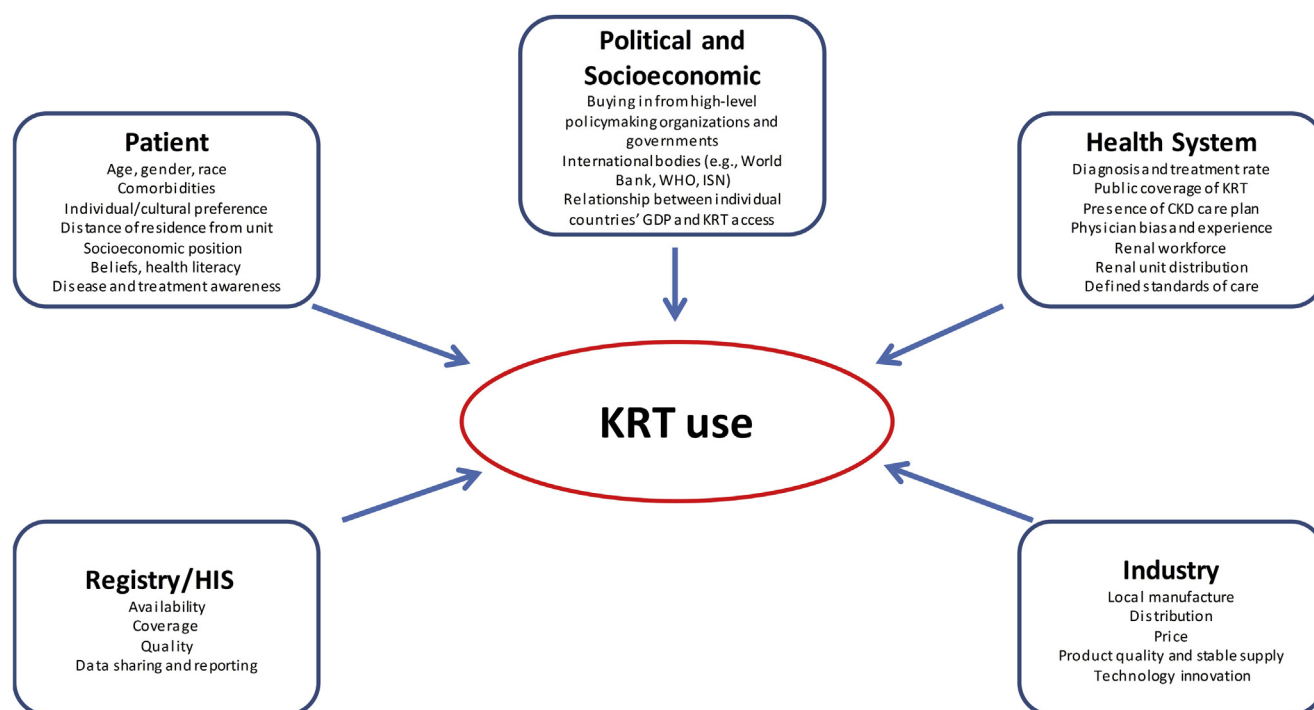
| Theme   | Area of focus  |
|---|--|
| Estimates of ESKD burden and treatment coverage | Explain the reasons for and monitor global differences in the incidence and prevalence of ESKD, ESKD care, and chosen modality of ESKD care                |
| Advocacy  | Develop an approach to advocate for integrated ESKD care in LMICs  |
| Education and training/workforce                | Develop locally appropriate strategies to enhance health workforce capacity  |
| Financing/funding models                        | Develop financial strategies and funding models to ensure equitable integrated ESKD care   |
| Ethics  | Enunciate ethical principles surrounding ESKD care   |
| Dialysis  | Define, recommend, apply, and develop a monitoring framework for minimum and optimal safety and quality standards for peritoneal dialysis and hemodialysis |
| Transplantation                                 | Define the key considerations for expansion of kidney transplantation as a component of integrated ESKD care   |
| Conservative care                               | Define the key considerations and development of conservative care as a component of integrated ESKD care  |

ESKD, end-stage kidney disease; LMIC, lower-middle-income country.





**Figure 2 | (a) Prevalence and (b) incidence rates of end-stage kidney disease (ESKD) (treated), dialysis, hemodialysis, peritoneal dialysis, kidney transplantation (Tx), and donor type in high-income countries (HICs) versus non-HICs.** Designation as non-HIC is based on World Bank country classification and includes 3 country groups: upper-middle-income countries (UMIC), lower-middle-income countries (LMIC), and low-income countries (LIC). ESKD includes all kidney replacement therapy components: dialysis + transplant. Dialysis includes all dialysis treatment modalities: hemodialysis + peritoneal dialysis. Data source: [Supplementary Table S2](#). pmp, per million populations.



**Figure 3 | Factors related to national, regional, and global variations in the incidence of treated and untreated end-stage kidney disease.** CKD, chronic kidney disease; GDP, gross domestic product; HIS, health information system; ISN, International Society of Nephrology; KRT, kidney replacement therapy; WHO, World Health Organization.

and to monitor the quality of care and outcomes. A minimum data set will (i) help health care professionals and people with ESKD make better-informed treatment decisions; and (ii) capture serious health-related suffering in people with ESKD for inclusion in global health reports.

Renal registries in countries and regions with low or relatively limited resources, such as Chad, Guinea, Niger, Tunisia, South Africa, Thailand, Malaysia, and several countries in Latin America (Bolivia, Colombia, Cuba, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Paraguay, Peru, Dominican Republic, and Venezuela) have demonstrated the potential of registries to highlight inequitable KRT access and help support policy decisions in favor of providing additional resources for ESKD care.<sup>13,14,29–34</sup> For instance, the huge gap in access to KRT between the private and public sectors demonstrated by the South Africa Renal Registry<sup>35</sup> is being used to advocate for increased access to KRT in the public sector in South Africa. These experiences should be drawn upon to help establish successful registries in other resource-limited countries.

Another possible strategy is incorporating data from resource-limited countries into existing registries, as has happened on occasion with North African countries contributing to the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) Registry<sup>30,33</sup> and the United States Renal Data System (USRDS) registry.<sup>12</sup> The increasing number of countries included in the Latin American Registry of Dialysis and Transplantation (currently collecting information on 20 countries of the region) is another example of the incorporation of resource-limited countries into existing

registries.<sup>34</sup> Pacific Island countries (e.g., Fiji) could leverage the infrastructure and collaborative expertise of the Australian and New Zealand Dialysis and Transplant (ANZDATA) Registry. Recently, agreement was reached between the African Association of Nephrology and the African Paediatric Nephrology Association to establish the African Renal Registry, which will use the shared web-based technology platform and common data dictionary of the South African Renal Registry.<sup>30</sup>

Registry data could be linked with geographic information systems to identify ESKD “hot spots” and areas where there are major mismatches between KRT supply and demand.<sup>36</sup> Registry data should be further enhanced by linkages with country population data, death registries, and other mortality data sets (e.g. Global Burden of Disease data), where possible. Registry output and reports should also be freely accessible online to maximize reach, transparency, and impact.<sup>30,37</sup>

Benchmarking will be facilitated by developing standardized definitions and terminology (data dictionary) for registries and also by the establishment of a minimum to be collected by all renal registries. For example, ESKD is variously defined around the world, ranging from absolute requirement for KRT to estimated glomerular filtration rate < 15 ml/min per 1.73 m<sup>2</sup>.<sup>38</sup> This definition and other important variables collected in registries need to be harmonized. Defining conservative care for capture by registries has proven challenging, with limited data available on numbers treated conservatively (nondialysis care) and the components and quality of conservative care. It is necessary to define the initiation of conservative care if registries are to measure it

**Table 3 | Explain the reasons for and monitor global differences in the incidence and prevalence of ESKD, ESKD care, and modality of ESKD care**

| Activities   | Partners   | Deliverables   |
|--|--|--|
| <b>Improve estimates of the incidence and prevalence of ESKD and ESKD care, including capturing KRT modality, and outcomes</b>   |  |  |
| Establish and enable ESKD registries in all countries:<br>- Make outputs, industry databases, and reports freely accessible online<br>- Integrate all aspects of ESKD care (adult and pediatric) into existing and new registries<br>- Link with geographic information systems, death registries, or other mortality data sets<br>- Explore mobile technology to access individual data<br>- Compare ESKD registries with national population data<br>- Supplement with observational studies (e.g., DOPPS)<br>- Develop a common, standardized data dictionary | Existing renal registries, patient and parent organizations, ISN and other national and regional professional associations, local and national health service providers and funders, industry, SharE-RR committee, experts in data linkage | - Survey and inventory of existing renal registries (as part of GKHA and SHarE-RR projects)<br>- ESKD Care Registry resource hub<br>- Published map of ESKD “hot spots” within regions and countries<br>- Collated reports of the proportion of patients dying from untreated ESKD in each country<br>- Published factors associated with reduced access to KRT<br>- Publicly searchable registry and database reports<br>- Publicly available data dictionary |
| Improve measurements of organ donation, transplantation, and outcomes  | CTS, established registries, ONT-WHO GODT  | - All countries contributing to registries<br>- Published annual outcome statistics of donors and transplant recipients<br>- All member states submitting data to ONT-WHO GODT   |
| Develop scholarships for training in epidemiology and registries   | ISN and other national and regional professional associations, local and national health service providers and funders, industry   | - ISN and other professional association scholarships  |

CTS, Collaborative Transplant Study; DOPPS, Dialysis Outcomes and Practice Patterns Study; ESKD, end-stage kidney disease; GKHA, Global Kidney Health Atlas; ISN, International Society of Nephrology; KRT, kidney replacement therapy; ONT-WHO GODT, Spanish Transplant Organization-World Health Organization Global Observatory on Dialysis and Transplantation; SharE-RR, sharing expertise to support the set-up of renal registries.

and report on quality. For similar reasons, it is necessary to agree on a definition for discontinuation of dialysis.

The prime focus of renal registries should shift from being modality-centered to person-centered KRT so that the journeys of patients with ESKD can be followed, monitored, and mapped along the continuum of ESKD care. Key patient-centered performance indicators should be captured to measure quality of care, including conservative care, which is often recorded poorly or not at all. In the same vein, registries should be integrated within countries and regions, such that pediatric and adult registries are combined and all forms of ESKD care (including dialysis, transplantation, comprehensive conservative care, and choice-restricted conservative care) are captured. Scholarship opportunities to specifically provide registry training and experience could help in the development and implementation of local registries, as had been demonstrated by previous Latin American Society of Nephrology and Hypertension (SLANH)-European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) fellowships in epidemiology and registries.

The scope of data that should be collected and collated is more than can be captured routinely by registries alone. Multiple sources of data, some of which can be linked to registry data, can be obtained during care of individual patients and from health systems. Examples include routinely collected clinical data and data obtained from dialysis machines and other equipment. Such data can be used to

evaluate ESKD care at multiple levels, including that of the individual patient, kidney unit, and geographic region.

## **Theme 2: advocacy. Develop an approach to advocate for integrated ESKD care in LMICs**

Countries are responding to the challenge of kidney disease and/or failure in different ways,<sup>39</sup> with variable provision of the components of a kidney care strategy (prevention, supportive care, conservative care, kidney transplantation, and an appropriate mix of dialysis modalities). The variability in approaches may be due to differences in the burden of disease, available human or financial resources, cost structures (e.g., relative cost of labor vs. supplies), cultural and religious considerations, political context, and competing interests from other stakeholders (including governments, other payers, patients and families, drug and device companies, dialysis providers, nephrologists, and other health care workers).<sup>40</sup> Decisions to establish dialysis services without sufficient consideration of the other components of a kidney care strategy are of particular concern — and are often made without effective representation and guidance from the kidney care community.

The current approach to kidney disease in many countries is neither sufficient (in terms of providing equitable access to high-quality care) nor sustainable (for the patient, health system, economy, and society) and demands the urgent attention of governments, policy makers, and the medical community.

There is currently no agreed-upon global framework or approach that LMIC governments can use to establish and/or scale up programs to prevent and treat CKD. Many of the existing WHO “best buys” for NCDs<sup>41</sup> will help to prevent progressive loss of kidney function and thus the burden of ESKD. However, there is no agreed “best buy” list of diagnostic tests or treatments for kidney diseases. Moreover, the CKD burden in many geographic areas is not explained by the commonly recognized risk factor clusters against which the current NCD best buys have been developed. This information would be useful to governments and health authorities that seek to develop integrated kidney care programs. In addition, there is a lack of information on how to successfully implement such programs. Case studies that summarize lessons learned from the global experience with kidney care programs would be a useful advocacy tool and are being developed. If selected carefully, such tools could be used by stakeholders to advocate for an integrated approach to kidney care (including ESKD) within a context of universal health coverage (UHC) and with an emphasis on preventive care. Activities to advocate for integrated ESKD care are discussed below and summarized in Table 4.

**Develop a framework that LMIC governments can use to establish and/or scale up programs for preventing CKD and providing ESKD care.** The high cost of dialysis and the morbidity and mortality associated with ESKD emphasize the high value of primary and secondary prevention. The expertise, medications, and diagnostic tests required to slow or prevent progressive kidney function loss are relatively inexpensive and could be scaled and spread in conjunction with other public health programs for prevention and control of chronic diseases.<sup>42</sup> Given that the cost per quality-adjusted life year (QALY) associated with providing such preventive care is markedly more favorable than dialysis care,<sup>42</sup> it is rational to prioritize publicly funded preventive care rather than publicly funded KRT. The ISN therefore accords the highest priority to prevention, and all capacity-building programs of the ISN and its partners are predicated on the requirement that there be a focus on prevention and other early interventions. Similarly, because not all patients with ESKD will benefit from and/or have access to KRT, expanded access to comprehensive conservative care (see theme 8) will improve patient outcomes and the experience of patients and families, and providing access to publicly funded comprehensive conservative care should receive priority.

When KRT is contemplated, kidney transplantation offers for suitable patients the best outcomes at the lowest cost, compared with dialysis, at least when provided in the right conditions.<sup>6</sup> Although HD is often considered first by countries seeking to develop a dialysis program, PD usually offers similar outcomes at lower costs to the health care system.<sup>43,44</sup> PD is especially appropriate for adolescents, children, and infants. Assuming that a well-run dialysis program can be established, the choice to favor PD over HD or to allow free choice by the patient should be supported by robust local health economic studies (theme 4).

Although these general principles for resource allocation (summarized in Table 5) are widely accepted, there are some practical barriers to their application. First, kidney transplantation requires multiple ancillary components (e.g., surgical expertise and facilities and access to tissue-typing laboratories) that may be difficult for LMICs to develop and sustain.<sup>45</sup> Because these services all involve certain fixed costs that are amortized across the total number of transplants done, the cost per transplant can be unreasonably high in settings where programs are new and/or perform low numbers of transplants. One option for countries in this position could be to partner with countries with more established programs, which would allow for shared resources, access to specialized training, and a pathway to improve local capacity. This assumes that adequate postoperative and chronic follow-up can be done locally. Second, patients whose transplants experience primary nonfunction or eventually fail will die of ESKD without dialysis support. Therefore, even in settings where kidney transplantation is successfully implemented as the preferred mode of KRT, dialysis capacity will be required. Third, although PD is generally less expensive than HD, there are settings where this is not the case—especially those where PD fluids and supplies are expensive (e.g., due to tariffs or lack of competition), or where skilled labor is relatively cheap (favoring HD because nursing care is a key driver of costs for this therapy but is not much needed to provide PD).<sup>46</sup> Therefore, flexibility is needed in applying these principles in different settings.

The 4 principles (in Table 5) are supported by evidence, but such evidence is not always summarized in a format that is useful to decision makers, may not apply to all LMIC settings, and may not have been recently updated. To be maximally useful to decision makers in LMICs, new evidence summaries (rapid reviews, systematic reviews, and economic analyses) are required that will provide updated and accessible information to support decision-making on kidney care programs. In addition, data that facilitate application of general principles in real-world settings would be beneficial. For example, identifying the threshold cost for PD fluids at which PD becomes more expensive than HD would help to identify settings in which principle 4 (Table 5) may not apply. Similarly, local information on the incremental cost of PD compared with HD would help decision makers to understand the net financial costs of a “free choice” strategy to dialysis modality selection. Therefore, there is an urgent need to produce and disseminate these summaries in partnership with end users.

There are several models that could be considered for organizing and funding kidney care programs, each with their own advantages and disadvantages. A summary of these models would be a useful adjunct to the summary of evidence related to the clinical services that should be provided and should be developed and disseminated in parallel with the former. Table 6 indicates a potential pathway for countries to develop a model of integrated kidney care, based on the experience of successful initiatives in countries such as Taiwan and Japan.



**Table 4 | Develop an approach to advocate for integrated ESKD care in LMICs**

| Activities   | Partners   | Deliverables  |
|--|--|---|
| <b>Develop a framework that LMIC governments can use to establish and/or scale up programs for preventing CKD and providing ESKD care</b>  |  |   |
| <ul style="list-style-type: none"><li>- Identify and/or produce literature syntheses to support the development of a national kidney care program</li><li>- Develop a tool that describes and justifies the principles behind establishing a national kidney care program</li></ul>  | <p>Cochrane Collaboration, university-based research groups</p> <p>WHO, government officials, nephrology societies, kidney foundations, patient groups, academia/health economists</p>       | <ul style="list-style-type: none"><li>- Document library</li><li>- Primary rapid reviews, systematic reviews, and economic analyses</li><li>- Scientific publication</li><li>- Brief technical report</li></ul>                                     |
| <b>Support stakeholders in advocating for integrated kidney care programs within their countries</b>   |  |   |
| <ul style="list-style-type: none"><li>- Develop and disseminate an advocacy tool kit for stakeholders' use</li><li>- Educate patients and families about CKD/ESKD and their rights/options in all aspects of treatment</li><li>- Use World Kidney Day (WKD) to highlight education and lobby governments</li></ul>   | <p>ISN advocacy portfolio, patient and parent groups, kidney foundations, national and regional nephrology societies, medical communities, organ donor initiatives</p>                       | <ul style="list-style-type: none"><li>- Key messages, infographics, economic analyses, case studies</li><li>- Established community groups with medical staff and families to drive treatment action campaign</li><li>- Annual WKD events</li></ul> |
| <b>Develop country-specific patient engagement strategies</b>  |  |   |
| <ul style="list-style-type: none"><li>- Conduct consumer engagement workshops in each country to:<ul style="list-style-type: none"><li>• Identify, promote, and implement effective community involvement strategies in registries</li><li>• Advise strategies for converting epidemiology information into patient-centered information</li><li>• Determine patient-relevant clinical priorities in ESKD care</li><li>• Determine research priorities in ESKD</li><li>• Define barriers to ESKD care</li><li>• Define enablers of ESKD care</li><li>• Establish patient ESKD advisory group in each country</li></ul></li></ul> | <p>Patient and parent organizations, ISN and other national and regional professional associations, local and national health service providers and funders, industry, governments, NGOs</p> | <ul style="list-style-type: none"><li>- Annual report detailing consumer engagement workshops held</li><li>- Register of patient ESKD advisory groups established in each country</li></ul>   |

CKD, chronic kidney disease; ESKD, end-stage kidney disease; ISN, International Society of Nephrology; LMICs, lower-middle-income countries; NGOs, nongovernment organizations; WHO, World Health Organization.

Decision makers in LMICs would benefit from a tool that describes and justifies the principles behind establishing a national kidney care program, including the 2 forms of evidence summarized above. This tool should present the 4 principles (in Table 5), and identify the preparatory work that countries must do before applying the principles (e.g., assess burden of kidney disease and ESKD, identify existing human capacity and relevant infrastructure, and consider and agree on health policy priorities). The tool should also make explicit the above-mentioned factors that may prevent a country from developing kidney care services in the order implied by the 4 principles, as well as suggesting metrics that help to inform countries when offering a more sophisticated kidney care program (e.g., what proportion of the population should have reasonable access to preventive services and supportive care before a kidney transplantation program is implemented, developing equitable and transparent rationing policies for access to dialysis). Care needs to be taken to ensure that supportive and/or palliative care is seen as an essential, integral component of comprehensive ESKD care, as it is with oncology and AIDS care. Priorities for spending on KRT programs need to be agreed upon by patient groups, the public, health care professionals, and policy makers.

**Support stakeholders in advocating for integrated kidney care programs within their countries.** From an advocacy perspective, current global efforts to establish UHC and the focus on NCDs are useful opportunities in making a case for change in kidney care.<sup>47</sup> In this context, there is a specific opportunity

to set out what an essential package of health services might look like for kidney care under UHC—and to emphasize that treatments for preventing and managing will often help to prevent and treat other NCDs such as diabetes and vascular disease. In such a fully integrated, people-centered health system, people with ESKD need the education and support to choose from the range of available care modalities—optimally HD, PD, transplantation, and comprehensive conservative care—and have their health-related quality of life (HRQoL) and well-being optimized on that modality. Potential stakeholders in this objective include health facilities, patient organizations, and national and/or regional nephrology societies. These stakeholders would benefit from tool kits and education that support them to advocate for rational kidney care programs. The tools would need to acknowledge and respond to the highly variable contexts, health systems, and large number of stakeholders that are involved within and across the different LMIC audiences.

It would be critical to ensure that these advocacy tools are aligned with the messaging for decision makers (above), as well as with the messaging in other relevant documents from key stakeholders such as ISN, Kidney Disease: Improving Global Outcome (KDIGO),<sup>40</sup> WHO and the HEARTS technical guidance initiative.<sup>7</sup>

**Develop country-specific patient engagement strategies.** Adults and children with advanced CKD experience high symptom burden and have complex health and social care needs.<sup>48–51</sup> Involvement of patients and caregivers is

**Table 5 | Principles of establishing a comprehensive kidney care program**

1. Interventions to slow or prevent progression of kidney disease to ESKD are effective, are highly cost-efficient, have synergies for the prevention and management of diabetes and vascular disease, and are easily integrated with other programs aimed at NCD prevention and control. Such preventive care should be the highest priority for kidney care programs in LMICs.
2. Supportive care and comprehensive conservative care programs should be established in parallel with preventive care programs. For LMICs, there is a need to agree on an essential package of resources and interventions for people with CKD and ESKD required to minimize the burden of serious (kidney) health-related suffering.
3. Among KRT modalities, kidney transplantation in suitable patients is associated with the best clinical outcomes at the lowest cost.
4. PD is associated with outcomes that are similar to those for HD. For LMICs that are contemplating chronic dialysis programs, whether PD should be prioritized over HD or free choice is allowed should be based on cost evaluation. Local manufacture of PD solutions may help to realize the potential economic benefits of PD.

CKD, chronic kidney disease; ESKD, end-stage kidney disease; HD, hemodialysis; KRT, kidney replacement therapy; LMICs, lower-middle-income countries; NCD, non-communicable disease; PD, peritoneal dialysis.

critically important to ensuring that planning of ESKD care, within the overall context of health care, meets consumer need and is appropriately prioritized. Patient involvement in research priority setting is increasing in frequency but still relatively rare,<sup>52</sup> and it is not currently known to what extent patients participate in, and influence, ESKD care planning in different countries around the world. This knowledge gap could be addressed through surveys and gray literature review, supplemented by qualitative research in patients and caregivers to identify barriers and enablers of ESKD care in different countries. Patient involvement, such as in the CAN-SOLVE-CKD Network,<sup>53</sup> would also help to improve

transparency in different countries regarding criteria for patient access to KRT. Additionally, initiatives such as Standardised Outcomes in Nephrology (SONG) have involved patients as important stakeholders in the definition of relevant clinical outcomes for research purposes in ESKD.<sup>54</sup>

In relation to transplantation, patient involvement can help build community support for deceased organ donation and promote transparency in allocation of kidneys and acceptance of patients onto waiting lists. Closely aligned with this is community engagement and education. Promoting the community's understanding of the concepts of death determination and the benefits of organ donation will be a benefit to society. In many societies, it would be essential to involve local religious, traditional, and cultural leaders in the development of patient education and awareness programs.

### **Theme 3: education and training/workforce. Develop locally appropriate strategies to enhance health workforce capacity**

As stated in theme 1, there are important gaps in the organization, knowledge, and practice of the health care workforce in ESKD care around the world—from the standpoint of physicians, nurses, and technicians. This is particularly true in LMICs, where there is often a lack of adequate education and training programs and funding. Adequate care for patients with ESKD (dialysis, transplantation, and conservative care) is not possible without a sufficiently trained and appropriately distributed workforce.<sup>55</sup> Activities to evaluate and enhance the nephrology workforce are discussed below and summarized in Table 7.

**Evaluate workforce and its training.** If sustainable ESKD care programs are to be developed, an initial, important first step is to collect accurate information about the number,

**Table 6 | Suggested pathways and strategies for developing integrated CKD and ESKD care**

| Pathways  | Partners  | Actions  |
|---|---|--|
| Understand ESKD burden at national and local level            | National health administration<br>National nephrology society   | CKD/ESKD registry<br>Epidemiology studies<br>Risk factor identification<br>Target population definition                            |
| CKD or ESKD committee at national or nephrology society level | National health administration<br>National nephrology society<br>Nephrologist as core leadership<br>Patient organizations     | CKD prevention program<br>Multidisciplinary care program<br>Replacement therapy quality control<br>Renal transplantation promotion |
| Standardization for integrated CKD and ESKD care              | National health administration<br>National nephrology society<br>International societies (ISN, regional societies, WHO, etc.) | CKD guideline<br>Dialysis guideline<br>Transplantation guideline   |
| Implementation of integrated CKD and ESKD care system         | Primary and secondary care physicians<br>Multidisciplinary health care teams<br>Patient organizations                         | Multidisciplinary and multi-professional care approaches   |
| Sustainability and quality improvement                        | National health administration<br>Social scientists, health economists, industry  | Funding assurance and health care coverage, bulk-buying dialysis supplies and immunosuppressive therapy                            |
| Outcome measures  | National health administration<br>National nephrology society   | Annual report and outcome assessment   |

CKD, chronic kidney disease; ESKD, end-stage kidney disease; ISN, International Society of Nephrology; WHO, World Health Organization.

**Table 7 | Strategies to evaluate and expand the health workforce capacity for sustainable ESKD care programs to develop**

| Activities   | Partners  | Deliverables  |
|--|---|---|
| <b>Evaluate workforce and its training</b>   |   |   |
| - Develop robust methodology to collect data, monitor, and make accurate renal workforce projections   | ISN, ISPD, IPNA, national and regional professional associations, local and national health service providers, dialysis providers, academic centers, health ministries  | - Report and needs assessment detailing available resources, barriers, facilitators, and projection of future needs   |
| - Evaluate the following: <ul style="list-style-type: none"> <li>• Training, education, and knowledge of physicians, nurses, and technicians</li> <li>• How existing national training programs and training provided by international organizations and academic centers contribute to expanding the workforce</li> <li>• Training models and the impact of accreditation; include models applied by other NCDs (e.g., AIDS, oncology, diabetes, and hypertension)</li> </ul> | ISN, ISPD, IPNA, WHO, academic centers, national and regional associations and societies, CME organizations, dialysis providers, national health programs, health ministries  | - Guidelines for the education and training of adequate ESKD care workforce<br>- Recommendations on the following: <ul style="list-style-type: none"> <li>• How the international community can best help with training programs in LMICs</li> <li>• How education of the workforce can best be organized and coordinated</li> <li>• Training lessons learned from other programs</li> <li>• Practicability of implementing an accreditation program</li> </ul> |
| <b>Develop strategies to enhance health workforce capacity</b>   |   |   |
| - Explore use and effectiveness of newer technologies to enhance training and care including telemedicine, online and web-based education, and training tools  | International, national, and regional professional associations, local and national health service providers and funders, industry, governments, NGOs, ISN and other national or regional nephrology societies, academic centers  | - A resource hub with tools that can be adopted or adapted by national organizations<br>- Online public health training in nephrology   |
| - Develop and evaluate effectiveness of regional networks for support, training, and continuing education  |   |   |
| - Promote ISN and other professional organization fellowships and training   | Academic Centres, ISN and other international, national, and regional professional associations and societies, local and national health service providers and funders, industry, governments, NGOs   | - Increased participation in nephrology fellowships and training<br>- Private or philanthropic support of training  |
| - Encourage PPP or PPI to support training with appropriate oversight ensuring that the right targets and messages are conveyed  |   |   |
| <b>Facilitate ESKD care-specific training to increase nephrology workforce</b>   |   |   |
| For PD and HD:<br>Prepare specific skill sets for the delivery of dialysis utilizing various personnel including nephrologists, primary care physicians, nurses, and technicians   | Professional nursing and technician organizations, national medical societies, academic centers, training centers, dialysis facilities, telemedicine  | - A resource hub with tools that can be adopted or adapted by national organizations  |
| For transplantation:<br>Develop handbook of requirements for transplant centers including transplant evaluations and longitudinal care after transplantation   | ISN-TTS sister transplant programs and tripartite relationships, local professional societies and colleges, ASHI  | - Established expertise in laboratory medicine and tissue typing<br>- Trained staff to address all requirements for a successful transplant program   |
| For conservative and supportive care:<br>Develop training in symptom assessment, communication skills, advance care planning, supportive care, and use of prognostic models  | Experts in communication skills training, multi-professional experts in supportive care, advance care planning and palliative care, ISN and other national and regional professional associations, patient and parent organizations, online resources for patients with ESKD and providers, existing academic-ministry partnerships | - A resource hub with tools that can be adopted or adapted by national organizations  |

ASHI, American Society for Histocompatibility and Immunogenetics; CME, continuing medical education; ESKD, end-stage kidney disease; HD, hemodialysis; IPNA, International Paediatric Nephrology Association; ISN, International Society of Nephrology; ISN-TTS, International Society of Nephrology - The Transplant Society; ISPD, International Society for Peritoneal Dialysis; LMICs, lower-middle-income countries; NCDs, noncommunicable diseases; NGOs, nongovernmental organizations; PD, peritoneal dialysis; PPI, public-private investment; PPP, public-private partnerships; WHO, World Health Organization.

competence, knowledge, and distribution of the existing workforce. The second step is to evaluate the available education and training programs and perform a needs assessment by identifying the barriers and facilitating factors that would inform development of appropriate training modules to provide and augment the basic and ongoing education of the workforce. The third step is to estimate the workforce and educational needs to support the expansion of ESKD care services. Learning from the experience of other specialties in

providing creative workforce and educational models should be explored. It is essential to focus attention not just on the nephrologists, but on primary care physicians and nonphysician workers, such as nurses, technicians, nutritionists, and social workers.<sup>56–58</sup> Because LMICs generally have limited personnel to provide ESKD care, nurses (registered and practical), technicians, and all-purpose assistants can be recruited and trained.<sup>59,60</sup> Similarly, limited availability of nephrologists requires engaging primary care physicians and

general surgeons for management of various aspects of ESKD care. Special mention should be made of the need of health care workers to manage children with ESKD.

International education and training programs, available through international organizations and global health programs of universities of other countries, can be helpful. While training in the local environment is ideal, organizations like ISN, International Society for Peritoneal Dialysis (ISPD), International Paediatric Nephrology Association (IPNA), and the Transplantation Society (TTS) have supported nephrologist and specialist training through their programs that permit those from LMICs to travel to training programs in HICs for varying durations (see [Supplementary Table S3](#)). Despite the risk of “brain drain,” recent data from these organizations indicate that the vast majority of trainees from LMICs who receive training in HICs return to their country of origin.<sup>61</sup> However, unless it is targeted to specific needs, training in HICs may not lead to accrual of knowledge relevant for practice and needs in LMICs. Short training periods focused on specific aspects of ESKD care, particularly involving hands-on care, can be useful. For example, focused hands-on training for both nurses and physicians to learn the basic principles of PD, techniques of PD catheter placement, and/or training algorithms for PD have been accomplished with short-term grants for physicians and nurses from LMICs visiting well-established dialysis centers.<sup>62</sup>

**Develop strategies to enhance health workforce capacity.** Exploring the use of newer technologies to enhance training is essential. Telemedicine health support systems, web-based education programs, webinars, ready availability of international guidelines with adaptation tools, web posting of a wide variety of educational materials (e.g., on ISN Academy: <https://www.theisn.org/education-external/isn-academy>), and online consultations and support can all help to support the education of personnel involved in ESKD care.<sup>63,64</sup> Examples of such programs include some of the educational initiatives instituted by the ISN, ISPD, and SLANH utilizing web-based education programs.

Renal workforce shortages are exceedingly common, particularly in LICs. For example, nephrologist densities vary over 1000-fold across the globe, averaging 0.32 pmp in LICs and 28.52 pmp in HICs.<sup>13,14</sup> Expanding the roles of available workforce could permit rapid expansion of ESKD care. Well-trained technicians, with appropriate education and supervision, could undertake many of the duties related to dialysis care.<sup>65</sup> For example, the expansion of PD in some HICs has been assisted by the use of technicians to provide support for patients at home (so-called assisted PD). Furthermore, primary care health workers with appropriate training can play an important role in the basic management of ESKD (S. Antwi, unpublished data).

The development of regional and local training programs focusing on locally relevant skills has the potential to increase access to, and improve the quality of, ESKD care. For example, the Red Cross War Memorial Children's Hospital in Cape Town, South Africa, has created a “kidney program”

that trains teams of doctors and nurses in hands-on skills to manage patients with acute kidney injury (AKI) in an intensive 1-week course, trains pediatricians from Africa for 1 and 2 years in nephrology, and trains adult nephrology fellows in pediatrics for 1 month. It is hoped that the latter will allow the trainees to at least address the basics of kidney disease in children upon their return to their local sites. The East African Renal Institute has recently been established in Nairobi to help train nephrology fellows from the region. The African Population and Health Research Centre (APHRC) in Kenya is working to encourage research into local issues in Africa, including a focus on chronic disease management.<sup>66</sup> The center has made it possible for doctoral training at African universities via the Consortium for Advanced Research Training in Africa (CARTA).<sup>61</sup> Regional training networks need to be developed for support, training, and continuing education of the ESKD workforce.

The importance of the involvement of dialysis facility providers in supporting the education of technicians, nurses, and physicians needs to be emphasized. This is the case whether the facility is developed by the government, hospital, physicians, or public-private partnerships (PPP) or investments (PPI). There needs to be assurances that this training conforms to international standards. Appropriate oversight of such training, therefore, needs to be organized based on approved criteria, such as those developed by the Board of Nephrology Examiners Nursing Technology (BONENT) in the USA and used in other countries such as India.

**Facilitate ESKD care-specific training to increase nephrology workforce.** Adequate education and training of the workforce requires that specific skill sets to cover all dimensions of ESKD care be defined. For example, for HD, training needs include concentrate chemistry, accurate weighing of patients, volume control, infection control, indications for vaccination of patients and staff, indications for patient isolation, risks and benefits of dialyzer reuse, and responses to intradialytic complications. For PD, specific educational dimensions that need to be addressed include the kinetics of PD, how the PD prescription is determined, how to deal with catheter infections and mechanical problems, how to manage other dialysis-related infections, and when to transfer patients to HD. Dietitians and social workers are often not part of the health care team for dialysis patients in LMICs. Dietitians should be trained through local institutions, and when not available, nephrologists, nurses, primary care physicians, and technicians should be educated to discuss nutrition issues with patients.

Transplantation is a highly skilled, multidisciplinary procedure and requires a specialized workforce with the appropriate qualifications. In addition to transplant surgeons and nephrologists skilled at managing transplant patients, it requires anesthetists, nurses, pharmacists, histopathologists, laboratory technicians, and scientists to run a human tissue-typing laboratory and dialysis backup. Training in supportive and conservative care is often lacking, even in HICs. Clinician (nurse, physician, and allied health personnel) training in



symptom assessment, communication skills, advance care planning, supportive care, and the use of prognostic models needs to be developed. Of particular importance is additional training of those caring for children and young people in LMICs, where ESKD care options are limited.

#### **Theme 4: financing/funding models. Develop financial strategies and funding models to ensure equitable integrated ESKD care**

There is compelling evidence to show that the availability, reach, and quality of ESKD care are directly linked to the wealth of a country and the proportion of resources spent on health care.<sup>27</sup> In a recent survey designed by ISN to collect information related to KRT in LICs and LMICs, government-funded KRT was associated with higher access to dialysis and transplantation, when compared with self-funded out-of-pocket (OOP) models of reimbursement (unpublished observation from the ISN Kidney Collection: <https://www.theisn.org/news/item/3282-presenting-the-kidney-collection-survey>). Therefore, development of locally appropriate financing models is key to establishing sustainable KRT programs throughout the world.

In affluent countries, dialysis is generally available to everyone who has the potential to benefit from it. On the other hand, as an expensive and cost-inefficient public health intervention, dialysis has been rated by the WHO to be a low priority for governments with limited resources.<sup>67</sup> Despite this, as documented by the GKHA,<sup>13,14</sup> HD is currently available in all countries of the world, including those that are unable to finance even basic health care services. Public funding for dialysis is available in 71% of countries, including 73% of LMICs and 44% of LICs.<sup>14</sup> Free dialysis at the point of care is available to some proportion of the population in 63% of countries.<sup>14</sup> However, the extent of the coverage is widely variable. An increasing number of countries are including coverage of dialysis in their UHC agenda under the sustainable development goals.

The decision to provide public funding for KRT is often driven by political rather than medical or economic factors, and is influenced by the perceived need and requirements of societies based on inputs from stakeholders in the overall context of values, human rights, equity, and self-determination by governments.<sup>68</sup> Each country selects an acceptable amount of KRT funding as a proportion of the overall health care budget. Given that chronic dialysis is so costly, universal coverage is not sustainable for most LMICs. Therefore, locally acceptable rationing criteria with transparent methods for their application need to be developed alongside sustainable funding models.<sup>69,70</sup>

Two general principles related to financing of health care<sup>71,72</sup> can be applied to dialysis: efficiency (optimal use of resources to minimize avoidable losses) and progressivity (making the service available in an equitable manner to the rich and the poor, such that those with unequal ability to pay do pay differentially). The latter is directly linked to UHC,

which stipulates that people should be able to access dialysis without risking financial ruin or impoverishment. In practice, however, there are significant departures from these principles in both HICs and LMICs. In particular, within many LMICs, salaried workers in the private and government sectors, as well as wealthy patients, are able to access dialysis that is not available to the rest of the population.<sup>73,74</sup>

Evidence of efficiency should come from health technology assessment (HTA), which evaluates the clinical effectiveness and cost-effectiveness of available ESKD treatment alternatives (HD, PD, transplant, and conservative care). Acting as a bridge between evidence and policy-making, HTA helps in efficient allocation of resources and discourages use of interventions whose cost is too high compared with benefits.<sup>75–78</sup>

PD is often promoted where dialysis is primarily funded by the government. For example, the government of Thailand conducted an HTA and determined that PD was the more cost-effective option while providing acceptable level of clinical effectiveness.<sup>20,78,79</sup> This prompted the adoption of a “PD-first” policy in which all eligible patients are offered PD, with the more expensive HD restricted only to those with a medical indication, or those with private insurance. Similar policies operate in Hong Kong. Other countries (Mexico, Guatemala, Canada, Spain, China, and Taiwan) have adopted a less strict “PD-preferred” policy.<sup>80</sup> In some LICs, however, the delivery of PD is expensive<sup>46</sup> because of the need to import supplies, the imposition of additional taxes and duties, and transportation costs. Finally, lack of well-designed health economic studies from a health system or societal perspective has prevented accurate cost determinations of competing KRT options in LMICs, leading to unfounded assumptions. For example, a recent study from India<sup>81</sup> showed that when the complete economic health system costs of HD including personnel salaries, capital infrastructure (building and equipment), and basic medical supplies were estimated, the cost to the system was found to be 4 to 8 times higher than estimated previous reports. This makes HD far more expensive than PD, contrary to the currently accepted narrative that PD is more expensive than HD in India.

Despite the superiority of transplantation for suitable subjects in terms of cost-effectiveness as well as clinical benefits, public financing of transplantation is not uniformly provided in LMICs. According to GKHA, public funding for transplantation was available in only 25% of LICs and 52% of LMICs.<sup>13</sup> This creates an anomaly in which a patient may choose to receive dialysis rather than a transplant just because the former is free at the point of care, whereas patients have to pay out-of-pocket for immunosuppressive drugs. Similarly, conservative care rather than dialysis may be more appropriate for certain patients<sup>11</sup> but is not supported by public funding because it is not perceived as a form of active care, but rather an admission of defeat. Activities to develop financial strategies and funding models to ensure equitable integrated ESKD care are discussed below and summarized in Table 8.

**Table 8 | Develop financial strategies and funding models to ensure equitable integrated ESKD care**

| Activities  | Partners   | Deliverables   |
|---|--|--|
| <b>Health care financing models and their applicability to KRT</b>  |  |  |
| <ul style="list-style-type: none"> <li>- Detail country-specific ESKD health care financing activities</li> <li>- Refine GKHA instrument to assess affordability, accessibility, and quality of ESKD care within and between countries</li> <li>- Augment GKHA data with expanded survey and gray literature review</li> <li>- Revise original documents included in the ISN collection and extract data on financing</li> </ul>  | Patient and parent organizations, ISN and other national and regional professional associations, local and national health service providers and funders, industry, health care policymakers, experts in health economics  | <ul style="list-style-type: none"> <li>- GKHA special report</li> <li>- Systematic review of published and gray literature</li> <li>- ISN collection data extract on financing in LMICs</li> </ul>   |
| <b>Compare impact of different models of provision and funding including public-private partnerships</b>  |  |  |
| Evaluate different ESKD care delivery models. Examine approaches to: <ul style="list-style-type: none"> <li>• Marketing</li> <li>• Tailoring services to the poor</li> <li>• Strategic purchasing</li> <li>• Lowering operating costs</li> <li>• Cross-subsidization</li> <li>• Optimizing human resources product and process reengineering</li> <li>• Increasing outreach</li> <li>• Information management</li> <li>• Integration and system stewardship</li> </ul> (A) Impact on equity<br>Survey of all countries regarding their current model in terms of funding and provision of care<br>(B) Impact on outcomes<br>Determine the outcomes of these different models in terms of hard endpoints | ISN, ISN regional boards, national societies, health economists, process evaluation experts, large dialysis providers<br><br><br><br><br><br><br><br><br><br><br>ISN GKHA, WHO, WHO's regional offices, national and regional nephrology societies<br><br>ISN GKHA, WHO, WHO's regional offices, national and regional nephrology societies, USRDS, ERA-EDTA | <ul style="list-style-type: none"> <li>- Case studies describing complete marketing, finance, and operations solutions</li> <li>- Identified opportunities for disruptive business process innovation</li> <li>- Thematic summary of different models</li> <li>- Description of impact in terms of:               <ul style="list-style-type: none"> <li>- Incidence and prevalence of HD, PD, TX, non-KRT initiatives</li> <li>- Demographics of those receiving or not receiving care</li> <li>- Survival and mortality</li> <li>- Percentage of health care budget and of GDP being spent on ESKD care</li> </ul> </li> </ul> |
| <b>Advocate for universal access to essential drugs and dialysis components for patients with ESKD</b>  |  |  |
| <ul style="list-style-type: none"> <li>- Review existing guidelines and care packages</li> <li>- Review drugs included in WHO strategic fund</li> <li>- Request WHO assistance in dealing with countries applying high fees or import duties on PD supplies</li> </ul>  | ISN, WHO, MOH, patient organizations, industry, KDIGO and other guideline-producing bodies   | <ul style="list-style-type: none"> <li>- Best practice recommendations for dialysis practice and affordable treatment of medical problems in patients with ESKD</li> <li>- Essential drug list, including immunosuppressive drugs for transplantation</li> <li>- Strategic purchasing guidelines</li> </ul>  |
| <b>Economic and societal return on investment</b>   |  |  |
| Evaluate cost-effectiveness in different settings: PD versus HD versus TX versus conservative care<br><br><br>Measure benefits to society: jobs created, skills, trade, knowledge generated, economic returns to society through better rehabilitation of patients<br>Develop narrative case study of countries where the approach changed at some point in time, and how that impacted outcomes  | MOH, health economists, process analysts, nephrologists, industry<br><br><br>Health economists, process analysts, nephrologists, social scientists<br><br>Specific participants  | <ul style="list-style-type: none"> <li>- Simulator tool or paper</li> <li>- Tools to calculate the differential costings between HD, PD, and transplantation that are region-specific and relevant for LMICs and HICs</li> <li>- Position paper</li> <li>- Tools to track returns on investment beyond deaths and DALYs</li> <li>- Thematic summary of different models</li> </ul>   |

DALYs, disability-adjusted life years; ERA-EDTA, European Renal Association-European Dialysis and Transplant Association; ESKD, end-stage kidney disease; GDP, gross domestic product; GKHA, Global Kidney Health Atlas; HD, hemodialysis; ISN, International Society of Nephrology; KDIGO, Kidney Disease: Improving Global Outcomes; KRT, kidney replacement therapy; LMICs, lower-middle-income countries; MOH, Ministry of Health; PD, peritoneal dialysis; TX, transplantation; USRDS, The United States Renal Data System; WHO, World Health Organization.

**Health care financing models and their applicability to KRT.** Health care financing models can be tax-based, insurance-based (social or private), or as OOP payments.<sup>83</sup> All 3 models are used to fund dialysis, with the first one being most

prevalent throughout wealthy countries. Even in countries such as the US, where general health care financing is done through insurance, dialysis is unique in being funded by general revenue. On the other hand, OOP is the most

common model of financing for dialysis in LMICs, which can lead to catastrophic health care expenditure and distress financing.<sup>81,82</sup> The model of funding and organization impacts on equity, irrespective of the budget available. For example, Colombia, with a gross domestic product per person (GDPc) of US \$7500, has a public health expenditure of 4.5% of GDP, whereas Mexico, with a GDPc over US \$10,000, spends only 3% of GDP on health, resulting in OOP expenditures of 25% and 50%, respectively.<sup>83–85</sup> However, Colombia has universal access to KRT, whereas Mexico does not. In India, even short periods of dialysis while awaiting kidney transplantation in a public-sector hospital caused catastrophic health care expenditure in over 80% of the population.<sup>82</sup>

Financing choices affect both efficiency and progressivity. Optimal design of dialysis financing cannot be isolated from the rest of health care in a welfare state, however. Even when providing dialysis to the poor from public funds is prioritized in principle, it has proven to be difficult to implement in practice. Experience from some jurisdictions that have introduced state-funded dialysis shows that other components of dialysis delivery that result in OOP expenditures (no matter how small their contribution) culminate in catastrophic health care expenditure and premature withdrawal from dialysis, thereby preventing attainment of equity.<sup>86</sup> Recognizing the need for reform, the government of the state of Andhra Pradesh in India provides a monthly grant of INR 2500 (US \$35) through direct cash transfer to offset OOP expenses incurred on dialysis.<sup>87</sup> Many countries have several different reimbursement schemes to fund KRT, which also diminish progressivity and perpetuate inequities in access to and outcomes of KRT.

Disparate financing models also create perverse incentives. For example, in some systems, nephrologists are paid per HD session, and hence stand to earn more from this modality, leading to disincentivizing of other KRT modalities. Preferential referral by nephrologists to HD units in which they have a financial stake constitutes additional financial conflict.<sup>69</sup> In view of this, many countries that fund dialysis through tax revenues have made nephrologist reimbursement uniform for both forms of dialysis.

Anecdotal reports have described informal insurance mechanisms such as charity, informal credit, and micro-financing for funding KRT.<sup>88</sup> While they reduce some of the financial burdens, they may not fully address all of these costs, and might add to inequity. The policy implications of such informal mechanisms for funding ESKD care need to be clearly understood.

Additional barriers are faced by some populations that are culturally deprioritized in some societies, such as women, children, and the elderly. Medical care for the primary breadwinners (usually men) is prioritized when there is a cap to the coverage amount. In a state-funded dialysis scheme in India, the female-to-male ratio was 1:3.5.<sup>86</sup>

Countries that have committed to supporting broad-based dialysis programs are likely to experience increase in demand

as the financial barrier is removed, which will force identification of new revenue sources (taxes), or disinvestment in other services. Alongside financing issues, governance and organizational factors need to be taken into account to optimize equitable use of limited resources when providing expensive ESKD care.<sup>21</sup>

The biennial GKHA surveys<sup>13,14</sup> should be refined to evaluate affordability, accessibility, and quality of ESKD care within and between countries. This information should be supplemented by a comprehensive review of published and gray literature. Data pertaining to ESKD care financing in LMICs can be extracted from the ISN Kidney Collection (<https://www.theisn.org/news/item/3282-presenting-the-kidney-collection-survey>).

**Compare impact of different models of provision and funding: public-private partnerships.** Governments may enter into agreements with the private sector to finance, build, and operate dialysis units for an agreed-upon return on investment. The rationale for using public-private partnerships (PPPs) emerges from the gaps in dialysis delivery and private investment in areas where there are limited public providers. Many LMICs that are developing dialysis as part of their UHC agenda are doing so through PPPs. PPP offers innovation opportunities, such as implementation of uniform protocols across a large number of units, reduced costs through strategic purchasing, better outcomes and service quality tracking through information technology services, and tying service delivery with requirements for workforce capacity-building and ancillary programs. For example, the PPP model in Colombia has been tied to promotion of kidney health, CKD prevention, free choice of KRT, and mandatory reporting.<sup>89</sup> Examples of PPP programs are to be found in India,<sup>90</sup> Russia,<sup>91</sup> Mexico,<sup>92</sup> and Swaziland.

While PPPs have permitted ESKD care services to expand,<sup>86</sup> there are few studies that have evaluated their ability to deliver efficiency gains in countries where access and equity are major concerns. The function of PPPs in LMICs can be further hampered by lack of strong governance and monitoring mechanisms, misbehavior of market forces, contract disputes, and lack of dispute resolution mechanisms. Further, the contractual workforce in PPPs may face lower pay and poor working conditions.<sup>93</sup> In some regions, PPP resulted in a decrease in PD utilization, with a significant increase in total dialysis expenditure.<sup>74,92,94</sup> We need more data on the performance of PPPs in dialysis delivery in different countries.

**Advocate for universal access to essential drugs and dialysis components for patients with ESKD.** While developing financing strategies for KRT, many countries omit coverage for ancillary medical needs.<sup>86</sup> As a result, patients end up incurring OOP medical expenses (antihypertensive medicines, erythropoiesis-stimulating agents for dialysis, vaccinations against hepatitis B virus, and immunosuppressive drugs for transplant), dialysis access procedures, and additional hospitalizations. A holistic approach to universal coverage of drug treatment and comprehensive patient care is required.

Use of generic medicines and development of strategic central purchasing policies have the potential to reduce costs.

**Economic and societal return on investment.** The economic and societal return on investment in ESKD care can also be measured in terms of monies saved when the most appropriate KRT model was implemented, jobs created (both for health care professionals and for patients), and skills, trade, and knowledge generated that can be leveraged to increase equitable access to health care. In terms of societal returns, part of the costs of ESKD care flow back to the community as they pay for nurses and technicians and allow ESKD patients to remain economically productive. This approach also allows development of tools to measure return on investment in economic terms, rather than only deaths and disability-adjusted life years (DALYs) averted.

As emphasized in themes 1 and 3, ESKD funding systems should allocate resources toward registries and workforce training. Finally, any responsible model to fund KRT must be coupled with population-based programs to detect early stages of CKD so that evidence-based public health interventions can be implemented to prevent or retard the progression to ESKD.<sup>4</sup> Such an approach has been adopted in many countries and is leading to either an arrest or even decline<sup>27,88</sup> in the incidence of new patients with ESKD.

#### **Theme 5: ethics. Enunciate ethical principles surrounding ESKD care**

Ethical challenges in ESKD care are encountered at all levels from policy development and administration to clinical practice. Questions at the policy level such as prioritization of CKD prevention versus treatment of advanced disease, equitable access to care for those with ESKD, rationing of resources (e.g., dialysis and transplantation), and decisions to initiate or continue KRT are relevant in all countries, but are especially challenging in LMICs<sup>21,95,96</sup> (see theme 2). For clinicians, decisions regarding starting and/or continuing dialysis may present multiple ethical dilemmas.<sup>97</sup> Many patients, especially the elderly, have multiple comorbidities and psychosocial complexities that complicate the qualitative assessment of potential treatment benefits. Decision-making is further complicated by diverse spiritual, cultural, religious, and socioeconomic backgrounds. In LMICs, the ethical complexity of bedside decision-making about ESKD is exacerbated by constraints in availability of treatment, financing of care, quality of treatment delivered, as well as corruption in some settings, leading to moral distress among patients, families, and health care workers.<sup>21</sup>

Despite early work on the ethics of dialysis,<sup>98</sup> ethics has been a neglected discipline in nephrology with the exception of kidney transplantation, which remains a popular topic for inter-professional research, commentary, and guideline development<sup>99</sup> (see theme 7). Limited ethical analysis and guidance relating to provision of integrated KRT, including dialysis, means that there are multiple gaps relating to the ethics of ESKD care.<sup>21,69,100</sup>

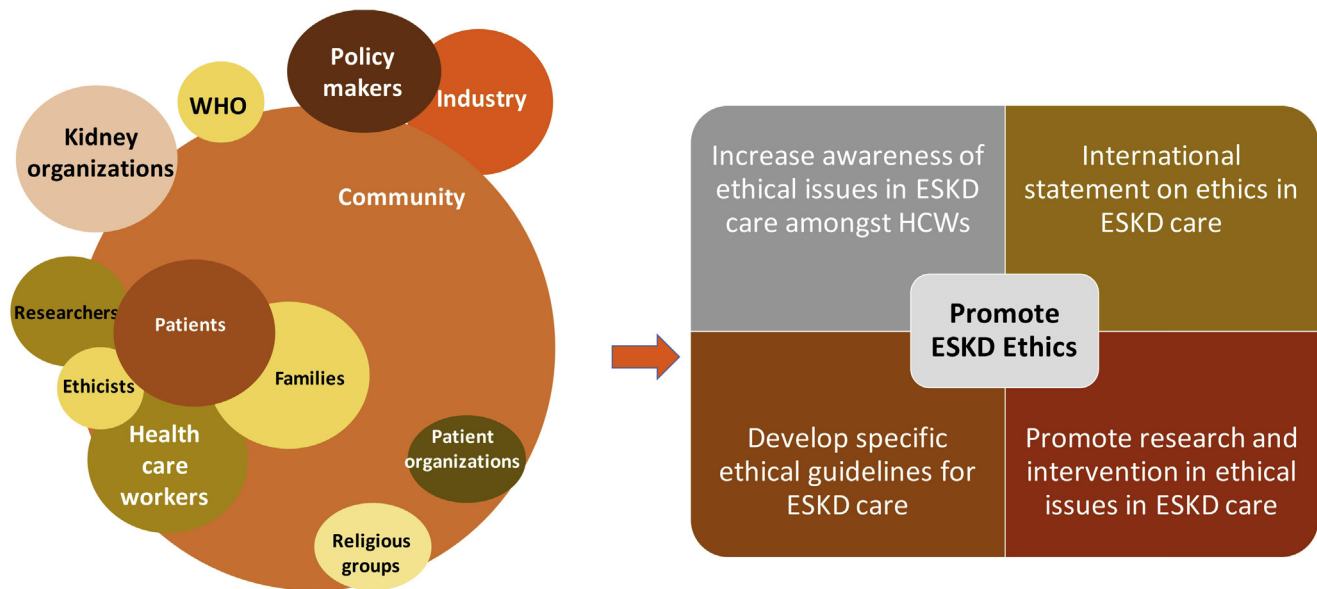
Work is needed to ensure a considered approach to the planning and delivery of ESKD care, to provide information and expert opinion to assist policy makers in deliberations concerning fairness in priority setting and resource allocation; and to promote shared and informed decision-making about management of kidney failure and provision of KRT in the context of health systems—including provision of appropriate supportive care for all patients, whether or not they receive dialysis.<sup>70,101–103</sup> Sensitivity to global diversity in culture; consideration for special groups such as the underserved, indigenous populations, migrants and refugees;<sup>104</sup> and use of reliable evidence of kidney disease burden and capacity of health systems are imperative to inform ethical decision-making.<sup>105</sup>

Evaluating practical issues identified above through an ethical lens is necessary to inform development of ethical frameworks to support decision-making, and to ensure that practical solutions are consistent with the values and preferences of the communities they are intended to benefit, as well as those responsible for their implementation. Exploration of the ethical aspects of ESKD care should build on past and current ethics work, not only in nephrology, but also in the context of public health, critical care, chronic disease management, and transplantation (Figure 4). Activities to enunciate ethical principles surrounding ESKD care are discussed below and summarized in Table 9.

**Develop an international professional statement articulating core ethical principles and values to guide policy and practice in ESKD care.** Specific ethical dilemmas relating to provision of ESKD care require elaboration at the local level or in the context of specific issues under the framework provided by the overarching principles and values regardless of diversities in environments. Health is a globally valued good, as is the right to be included in decision-making about matters concerning individuals and communities. Together, they provide the foundation for a common ethical framework to guide policy and practice in ESKD care around the world.

The development and communication of an international professional ethics statement addressing the spectrum of ESKD care, such as service planning, choice of type of KRT, and conservative care is needed to clarify the standards and goals of the global community of kidney care professionals. Such a statement would serve to inform development of local policy and practice, highlighting the importance of addressing equity concerns and optimization of access to kidney care in the context of local standards of care.<sup>106,107</sup> The availability of ethical guidance should enhance and promote equity in the quality of care for patients and their families, for example by assisting health care workers to advocate with and on behalf of patients and their families and communities. It could also reduce moral distress for health care workers confronting ethical issues in ESKD care, for example, when burdened with the responsibility for making rationing decisions in the absence of ethical or institutional guidance or when required to implement policies or work under circumstances which may be inconsistent with their own ethical values.<sup>21,108</sup>





**Figure 4 | The range of stakeholders involved in end-stage kidney disease (ESKD) care, highlighting the multipronged approach required to promote awareness of ethical challenges and support ethical practice pertaining to ESKD care.** HCWs, health care workers; WHO, World Health Organization.

**Raise awareness and understanding of ethical aspects of ESKD care among health professionals.** Moral distress among health care workers can lead to demoralization, regret of choice of profession, and feeling “burnt out,” and contribute to brain drain from LMICs.<sup>108,109</sup> Distress may come from a lack of guidance for clinical practice regarding access to KRT, limited or nonavailability of palliative and supportive care, and having to deliver care inconsistent with one’s own values. Examples include deciding whether or not a family breadwinner should receive potentially lifesaving KRT because of lack of health system or patient resources, or when patients and/or families insist on likely futile KRT simply because it is available. Physicians often feel powerless to advocate against restrictions imposed by the system, and lack of awareness of guidance<sup>110</sup> regarding ethical withholding or withdrawal of care may exacerbate moral distress.

In order to stimulate theoretical and applied work on the ethics of ESKD care, and to promote ethical practice in the delivery of ESKD care, health professionals must be able to recognize, understand, and appreciate the importance of ethical concerns that may arise in policy or practice, critically evaluate policies and practices from an ethical perspective, and contribute to actions aimed at addressing ethical concerns. Tools to approach ethical aspects of ESKD care, facilitate working through and articulating moral dilemmas at the bedside, and foster mutual support to reduce moral distress should be included in education and training activities to build skills and knowledge among the nephrology workforce. Ethical challenges should be explored in professional forums such as academic conferences and in academic publications, so as to stimulate discussion and encourage engagement with opportunities for collaboration.

**Increase inter-professional research, discussions, and interventions on ethical issues in ESKD care.** Development of effective and ethical solutions to the multidimensional challenges of providing appropriate ESKD care to all requires interdisciplinary research. Determining the fairest way to distribute treatment resources requires knowledge of the local health economics relating to KRT, the health care system infrastructure, population disease burdens, and community values and preferences.<sup>111–113</sup> Capacity building among researchers in local contexts is a prerequisite to support relevant and meaningful studies. Clinicians, researchers, ethicists, and health administrators must engage with community stakeholders, civil society, industry, policy makers, and those involved in advocacy and care delivery for related communicable and noncommunicable diseases.<sup>114</sup>

The development of a strategic plan for research in the ethics of ESKD care at international and national levels will help to establish priorities for multinational and multidisciplinary collaborative research.<sup>115</sup> This is particularly important given the global shortage of ethicists currently working on issues in nephrology and the limited ethics expertise available in some countries. A strategic plan will also help to inform research funding decisions by those seeking to invest in the ethics of ESKD care, and to guide the development of regional and national research activities.

**Develop issues papers and guidelines addressing specific ethical issues in ESKD care.** As Jha and colleagues and others have highlighted<sup>21,69,116</sup> and the deliberations of ISN’s 2nd Global Kidney Health Summit in 2018 have made evident, several ethical issues in ESKD care require urgent attention. In some countries, issues relating to end-of-life decision-making may be most acute, whereas in others, especially

**Table 9 | Enunciate ethical principles surrounding ESKD care**

| Activities  | Partners  | Deliverables   |
|---|---|--|
| <b>Develop an international professional statement articulating core ethical principles and values to guide policy and practice in ESKD care</b>  |   |  |
| - Develop statement with key stakeholders<br>- Promote on ISN website and in communication materials  | Consultations: WHO, patient groups, stakeholders in ISN, ASN, ERA-EDTA, and other nephrology societies, ethics experts from HICs and LMICs            | - International professional ethics statement on ESKD care<br>- Publication in nephrology, ethics, global health journals  |
| <b>Raise awareness and understanding of ethical aspects of ESKD care among health professionals</b>   |   |  |
| Develop educational activities and resources relating to ethics of ESKD patient care  | ISN members, professional associations (nurses, technicians, dietitians, social workers), bioethicists with an interest in nephrology, WHO, educators | - Webinar(s)<br>- Workshop(s) or special seminar(s) at nephrology conferences<br>- Slide decks<br>- Case library with ethical analysis for use in teaching   |
| Develop nephrology ethics and advocacy leadership and mentorship program to increase capacity:<br>- Identify potential partners, develop program, determine budget and outcomes<br>- Implement and evaluate a pilot program   | Universities with bioethics programs  | - Nephrology ethics and advocacy training curriculum (clinical, research, HPSR)<br>- Pilot program<br>- Tools to measure and reduce moral distress   |
| Develop manuscripts on each ethical principle identified above with theory and discussion from LMIC and HIC perspectives  | Clinicians in LMICs and HICs, clinical ethicists, public health ethicists   | Publication in nephrology, ethics, global health journals  |
| Encourage publications addressing ethical issues in ESKD care by increasing research and promoting awareness of such issues in the nephrology and bioethics communities   | Nephrology societies, International Association of Bioethics, biomedical journals   | Ethics page on the ISN website (under Advocacy) for collation of resources and promotion of opportunities for collaboration  |
| <b>Increase multidisciplinary research and interventions on ethical issues in ESKD care</b>   |   |  |
| - Survey ISN members and stakeholder groups to identify common ethical issues and concerns and priorities for research<br>- Develop a strategic plan for research in the ethics of ESKD care<br>- Build capacity among local researchers across disciplines<br>- Identify opportunities for funding of research in this field and develop funding applications<br>- Identify research themes and regional gaps to be addressed by ISN nephrology ethics fellows | Philanthropists, WHO, national ethics committees  | - Descriptive international study evaluating common ethical issues and priorities in ESKD care<br>- Strategic plan for research in the ethics of ESKD care<br>- Research training focus within ethics workshops at national and international meetings and integrated into nephrology ethics fellowships |
| <b>Develop issue papers and guidelines addressing specific ethical issues in ESKD care</b>  |   |  |
| Form working group(s) to investigate specific issues (informed by survey planned above) and develop ethical guidelines for policy and/or practice, including the issue of priority setting and/or allocation of resources for ESKD care   | Bioethicists, WHO, policy makers, national societies, ISN regional boards, public health ethicists  | Publication of issues papers and guidelines  |

ASN, American Society of Nephrology; ERA/EDTA, European Renal Association – European Dialysis and Transplant Association; ESKD, end-stage kidney disease; HICs, high-income countries; HPSR, Health Policy and Systems Research; ISN, International Society of Nephrology; LMICs, lower-middle-income countries; WHO, World Health Organization.

those with limited health resources, issues relating to justice in the distribution of resources may be prioritized. In addition, conflicts of interest—particularly financial ones—may inappropriately influence decision-making about many aspects of ESKD care if they are unrecognized and/or not managed appropriately.

The development and promulgation of papers exploring such issues and review of existing guidelines providing recommendations for ethical practice in ESKD and relevant conditions will enhance awareness and improve the quality of care received by patients and their families, reduce inconsistencies in policy and practice, improve fairness and efficiency, and reduce anxiety and distress that professionals, patients, and other decision-makers may experience when grappling with ethical uncertainty or

unethical practices. Highlighted here are examples of 2 priority areas for more focused ethical work.

- (i) Challenges in resource allocation are particularly acute and ethically complex in resource-limited settings.<sup>21,96,116,117</sup> The provision of ESKD care should aim to promote equity of access, such that criteria used to allocate public funding for ESKD care, or to determine eligibility for KRT, are primarily based on evidence-based medical parameters, not socioeconomic status.<sup>118–120</sup> However, in the absence of guidelines to govern resource allocation, the ability to pay for care is often the most influential, or the only, factor determining access to care. The extent to which funding issues may justifiably influence resource allocation decisions in provision of

ESKD care, if at all, is a topic deserving of substantial further work.

- (ii) While dialysis (or transplantation) may be life-saving, it may also impose significant burdens—economic, clinical, and social—on patients and their families and has important implications for the broader community.<sup>21,69</sup> Thus, even when there are few resource constraints directly influencing access to ESKD care, the potential benefits of various care modalities must be evaluated in comparison with the potential burdens and considered in the context of broader personal and societal goals.<sup>77,103</sup> Determining who should be involved in making such evaluations and how individuals or groups should be involved in decision-making requires careful ethical deliberation. Respect for autonomy is a widely accepted ethical norm in the context of health care delivery. However, operationalizing this may be complicated in some sociocultural and health care environments, and in the context of specific decision-making dilemmas.<sup>121,122</sup>

**Theme 6: dialysis. Define, recommend, apply, and develop a monitoring framework for minimum and optimal safety and quality standards for peritoneal dialysis and hemodialysis**

The quality of dialysis delivered to patients varies from country to country, region to region, and facility to facility. This is particularly so in countries without universal standards of care and governmental (or other organizational) oversight, including audits of quality of care. This can result in suboptimal or poor quality of care.<sup>123</sup> Oversight of dialysis care occurs in all HICs, usually based on adherence to standardized, evidence-based guidelines, tracking of outcome measures (e.g., mortality and hospitalizations), commercial oversight, and inputs of regulatory organizations, such as health care commissioners, insurance providers, and those dealing with technical specifications for machines, dialyzers, water, and dialysate purity. Many LMICs appear to have no or limited organized oversight systems to ensure that safe and effective care is provided.

Guidelines for HD and PD have been produced for more than 20 years in HICs. A wide range of guidelines have been developed in Europe, Australia, USA, and Canada. Comprehensive PD guidelines have been published dating back to 1998 by ISPD.<sup>124</sup> In addition to the national guidelines, nephrology societies, government (both national and regional) health departments, and dialysis facility owners have developed guidelines to reduce practice heterogeneity and improve quality and safety standards. The application of such standards and guidelines in LMICs is uncertain since the implementation of these guidelines generally assumes sufficient workforce and financial resources to support these levels of care and safety practices. It is important to understand how these standards can then be reasonably adapted and applied in LMICs, which often have limited workforce (theme 3) and financial resources (theme 4). Certainly, if standards from HICs are to be applied in LMICs, then the nephrology community in the country or region should appropriately modify the guidelines.

A major challenge facing LMICs is maintaining safety and good quality of care in a financially responsible way.<sup>20</sup> For example, it is worth noting that some ESKD services in LMICs are provided by small companies, particularly in smaller towns. This has permitted an expansion of ESKD care services to patients who otherwise would not have access to care. Overview of these organizations by government or national nephrology organizations to ensure adherence to appropriate standards of care is important and can facilitate the expansion of ESKD care services to these more remote areas. As already mentioned, some countries, such as Thailand,<sup>125</sup> have achieved cost reduction by means of a PD-first policy. This has been adopted as a governmental policy and has made universal KRT coverage possible. PD has a number of features that should be attractive to LMICs, including lower expense (depending on local manufacturing and/or low import duties and taxes), fewer technical demands, greater feasibility of use in remote regions, reduced need for trained staff, and fewer management challenges in the setting of natural disasters.<sup>126–128</sup> Practical problems in expanding PD programs include the training of individuals to insert catheters, the potential risk of infection, and the ability to obtain dialysate at an acceptable cost. While the latter problem could be ameliorated by local manufacture of PD solutions, this has been difficult to realize. Furthermore, the costs of distribution of supplies has limited the availability of PD in many LMICs.<sup>24,129</sup> It is important to note that provision of PD involves not only the provision of dialysis solutions but also the availability of satisfactory connection ports between PD solutions and the catheter and appropriate support systems. In addition, it needs to be appreciated that 10% to 15% of PD patients transfer to HD each year because of various complications; thus, having an HD facility available to help manage these patients is essential.

An important focus of the international nephrology community in supporting ESKD care in LMICs should be on the application of well-researched guidelines that are adapted to the resources and funding available in each country, using validated tools like ADAPTE<sup>130</sup> to ensure that safe, reasonably good-quality care is provided. Examples include incremental HD and PD programs, with initiation of dialysis with less than thrice weekly HD or reduced numbers of PD exchanges in patients with modest residual renal function.<sup>131–135</sup> This approach is important because it can lead to expanded care of patients with ESKD. However, careful attention to the amount of dialysis provided and the maintenance of basic standards of care remains critically important because limited dialysis will, in general, provide suboptimal dialysis in patients with no residual renal function.

New and innovative technology that reduces the cost of KRT and enhances access to and quality of KRT should be explored and remain a focus. Activities to define safe and minimum standards of dialysis and possible innovative approaches are summarized in Table 10.

**Table 10 | Define and apply minimum and optimal safety and quality standards for PD and HD**

| Activities  | Partners  | Deliverables  |
|---|---|---|
| <b>Define safe and minimum standards for sustainable dialysis treatment</b>   |   |   |
| <ul style="list-style-type: none"> <li>- ISN to establish a workgroup to review existing guidelines and well-established standards of care (in both HICs and LMICs) focusing on the applicability and flexibility necessary for care in individual lower-resource countries</li> <li>- Integrate local partners, patients, industry, and global organizations in the discussion</li> <li>- Disseminate the proposals at regional and national levels and through WHO, government agencies, nephrology organizations, and dialysis providers</li> <li>- Define the amount of dialysis to be provided and appropriate timing for the initiation of dialysis</li> <li>- Consider incremental dialysis for both HD and PD as way of reducing costs and optimizing care and quality of life of patients</li> <li>- Consider possible PD first program if PD solutions can be obtained in a practical, cost-effective manner</li> <li>- Apply international standards of water treatment</li> <li>- Consider dialyzer reprocessing with the assurance of conforming to international standards</li> <li>- Ensure careful monitoring of outcomes</li> <li>- Establish appropriate infection control practices, applying international standards</li> </ul> | <p>Affordable Dialysis Project, Kidney Care Network, PD-first programs, hospital programs, industry, NGOs, PPP, KDIGO, KDOQI CARI EBP, guidelines from national renal associations, ISN, AAMI water standards, international standards organizations, national societies, governments, WHO, MOH, national nephrology organizations, ISPD, ISHD, universities, US Centers for Disease Control and Prevention, university-based global health programs, patient organizations</p> | <ul style="list-style-type: none"> <li>- Set of recommendations adapted to local settings utilizing the ADAPTE<sup>130</sup> framework for: <ul style="list-style-type: none"> <li>• Pre-dialysis care, dialysis initiation, dialysis frequency and dose (HD and PD)</li> <li>• Recommendations for HD to include water treatment, dialyzer reuse, machine sterilization, monitoring and reporting safety and outcomes, infection control</li> <li>• Recommendations for PD to include catheter placement, connection systems, infection control, and possible development of local sources of dialysate and equipment</li> <li>• Recommendations for infection control to include prevention of access infection, infection control standards, patient isolation, vaccination of patients and staff, and careful monitoring of adverse events</li> </ul> </li> </ul> |
| <b>Propose innovative approaches to safe and sustainable dialysis</b>   |   |   |
| <ul style="list-style-type: none"> <li>- Determine feasibility of telemedicine utilization for staff training, monitoring patients, etc. (theme 3)</li> <li>- Explore innovative approaches to dialysis therapy, including creative use of solar energy, innovative and efficient water treatment, more cost-effective dialysis machinery, inexpensive manufacture of PD solutions, and reduction in plastic waste</li> </ul>   | <p>International and professional educational institutions, industry, ISN/ISPD, IPNA, EuroPD, ISHD, academic medical centers</p>  | <ul style="list-style-type: none"> <li>- Telemedicine consultation for remote areas</li> <li>- Support of new and innovative technologies</li> </ul>  |
| <b>Define safety standards for pediatric facilities</b>   |   |   |
| Review existing guidelines  | ISN, IPNA, ISPD, pediatrics societies   | Recommendations for pediatric units and care  |

AAMI, Association for the Advancement of Medical Instrumentation; CARI, Caring for Australasians with Renal Impairment; EBP, evidence based practice; ESKD, end-stage kidney disease; EuroPD, European Peritoneal Dialysis; HD, hemodialysis; HIC, high-income countries; ISHD, International Society for Haemodialysis; IPNA, International Paediatric Nephrology Association; ISN, International Society of Nephrology; ISPD, International Society for Peritoneal Dialysis; KDIGO, Kidney Disease: Improving Global Outcomes; KDOQI, Kidney Disease Outcomes Quality Initiative; LMICs, lower-middle-income countries; MOH, Ministry of Health; NGOs, nongovernmental organizations; PD, peritoneal dialysis; PPP, public-private partnerships; WHO, World Health Organization.

**Define safe and minimum standards for sustainable dialysis treatment.** To define safe and minimum standards for sustainable dialysis treatment, existing established guidelines such as Kidney Disease Outcomes Quality Initiative (KDOQI), KDIGO, European Renal Best Practices, Caring for Australasians with Renal Impairment (CARI), Canadian Society of Nephrology, SLANH, National Institute for Health and Care Excellence (NICE), etc., should be adapted to focus on their applicability to countries with limited resources in the context of availability of financial and workforce support. Documents that have been utilized in LMICs, such as Indian Guidelines,<sup>136</sup> as well as various hospital, academic, and commercial provider recommendations, such as those identified in the ISN Collection, provide additional guidance. Critical vetting and eventual acceptance of these approaches in individual countries or regions should involve the local nephrology community, patients, industry, and government and global health care organizations. Broad dissemination of the proposals is essential.

**Define safety standards for pediatric facilities.** PD is the preferred KRT modality in pediatrics, when transplantation is delayed or impractical, because it permits more flexibility of therapy. However in some countries, such as South Africa, if children with ESKD are judged not to be suitable candidates for transplant, chronic dialysis is not undertaken because there is no positive end point and the family may be put in a financially challenged state. Linking an adult and pediatric unit together may enhance sustainability. Pediatric-specific equipment may be difficult to source for stand-alone units but could be more easily purchased when linked to a larger adult unit (with increased numbers of patients).

#### **Theme 7: transplantation. Define the key considerations for expansion of kidney transplantation as a component of integrated ESKD care**

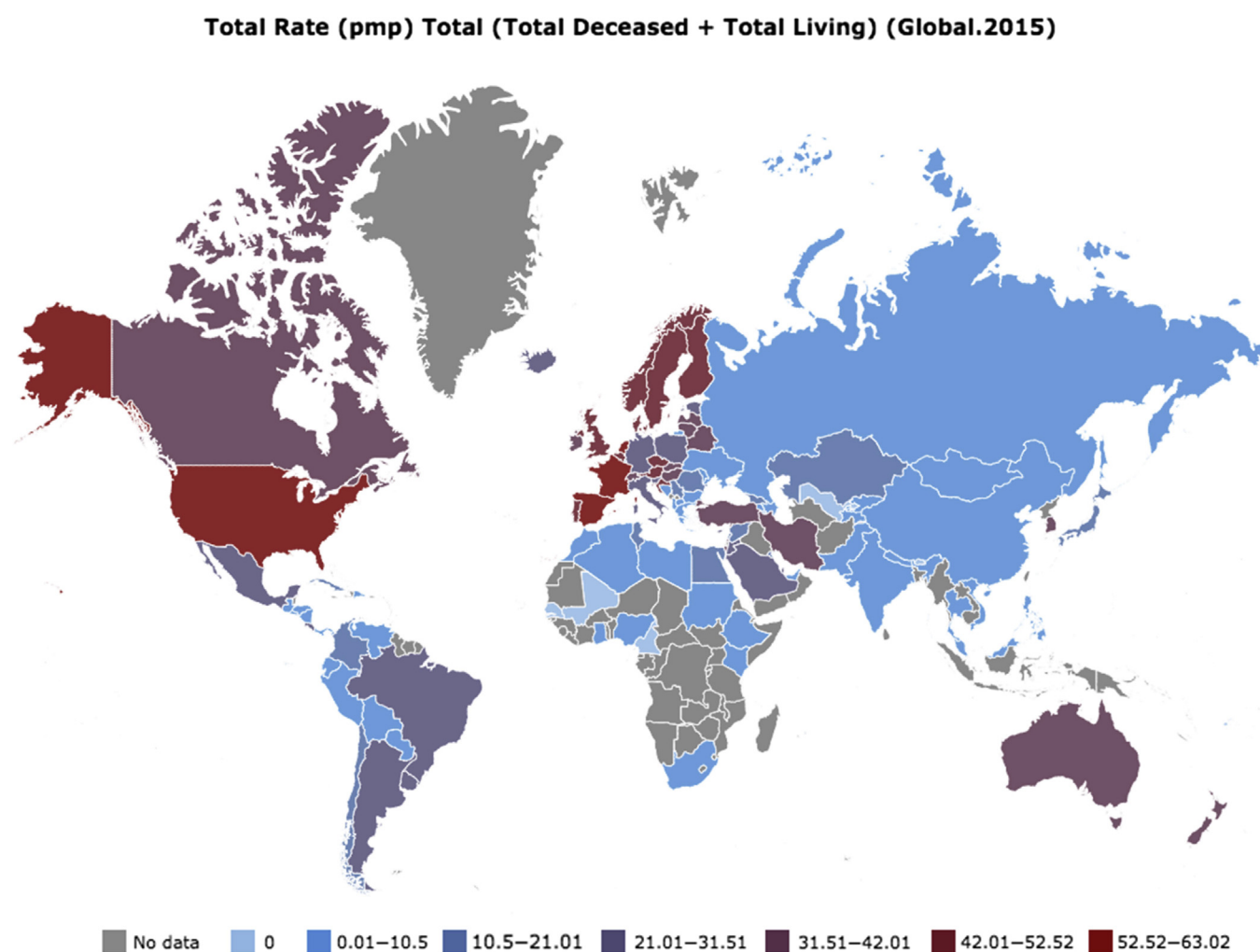
Transplantation is the preferred modality of care for ESKD in suitable subjects,<sup>6,8</sup> including for children because of the better quality of life and long-term survival.<sup>137</sup> However, there



are wide disparities in access and use and substantial risks to both donors and recipients associated with poor practices. According to the Global Observatory on Donation and Transplantation (GODT), 111 of the 192-member states of WHO provided data on transplantation activity to the global registry. Kidney transplants were performed in 102 of the 111 countries.<sup>138</sup> Living donor kidney transplants were performed in 98 countries, and deceased donor transplants in 76. Figure 5 shows the distribution of kidney transplant rates around the world. Kidney transplantation is nonexistent in some parts of the world, including much of Africa and parts of Southeast Asia, reflecting both cultural preferences and resource limitations. In particular, Africa has a very low transplant rate, with only 488 kidney transplants performed (0.4 pmp) in 2015 and a very variable distribution, as many countries have no transplantation programs.<sup>138</sup> The majority of transplants occur in HICs, and these regions generally have higher rates of deceased donation. In LMICs, deceased donors are poorly utilized because of an ineffective organ procurement network, lack of facilities for pre-transplant

investigation and taking care of potential donors, and poor public education.<sup>139</sup>

To achieve expansion, ideally transplantation services should be integrated into every national program of ESKD treatment as stated earlier (Table 5). As up to 50% of the ESKD population are treated by transplantation in several HICs,<sup>140</sup> this can be seen as a potential national benchmark for eligible patients. All these countries have national health care schemes and strong deceased kidney donor programs. For LMICs, an incremental objective relative to the development and sophistication of their health system needs to be developed. In addition, efforts should be undertaken to establish regional children transplant centers to optimize the use of scarce resources. Nearly all newly established ESKD care programs start with dialysis and have no transplantation. A policy focused solely on dialysis will be costly and may result in patients seeking transplantation in an unregulated environment, creating a market for organ trafficking. Activities to develop transplantation in LMICs are discussed below and in Table 11.



**Figure 5 | Total rate of deceased and live donor transplants in each region.** Reproduced from Global Observatory on Donation and Transplantation data, produced by the World Health Organization and Spanish Transplant Organization collaboration ([www.transplant-observatory.org](http://www.transplant-observatory.org)). pmp, per million population.

**Table 11 | Define the key considerations and role of kidney transplantation as a component of integrated ESKD care**

| Activities  | Partners   | Deliverables  |
|---|--|---|
| <b>Implement legislation for organ donation and safe transplantation in all countries</b>   |  |   |
| <ul style="list-style-type: none"><li>- Conduct survey to identify countries that lack or have inadequate legislation; survey state of transplant infrastructure</li><li>- Identify credentialed centers; identify countries with LD TX alone and those with LD + deceased donor programs</li><li>- Partner with local advocates, clinicians, patient groups to support development of legislation and lobby governments with respect to illegal practices (organ trafficking)</li><li>- Publish transparently all transplant activity in every country and integrate this information with dialysis activity</li></ul> | <p>WHO, ONT, local patient and support groups, local health workforce</p> <p>DICG, WHO, WHA, TTS, health departments</p> | <ul style="list-style-type: none"><li>- Countries identified with gaps in legislation</li><li>- Existing transplant service infrastructure assessed</li><li>- Implementation of legislation</li><li>- 100% of countries with transplant programs with legislation for organ donation and transplantation</li></ul>                          |
| <ul style="list-style-type: none"><li>- Develop guidance for ethical practice that is relevant to local resources and cultural factors</li></ul>  | <p>ISODP</p>   | <ul style="list-style-type: none"><li>- Increased global capture of activity and outcome data from integrated dialysis and transplant registries with systematic reporting of data to ONT-WHO GODT</li><li>- Established ethical guidance documents that support institutional best practice</li></ul>                                      |
| <b>Integrate health care plans that include transplantation</b>   |  |   |
| <ul style="list-style-type: none"><li>- Identify appropriate transplantation targets (% of all CKD5 and prevalent KRT patients) for each region; identify national and regional models for transplantation</li><li>- Include referral pathway for transplantation where appropriate</li></ul>   | <p>Health departments, TTS, ISN, IPTA, IPNA, professional societies and colleges, patient groups</p>                     | <ul style="list-style-type: none"><li>- Region-specific targets for proportion of KRT patients for whom transplantation would be appropriate; description of regional models</li><li>- A structured patient education and referral pathway for living and deceased donor transplantation that supports integration in each region</li></ul> |
| <b>Promote organ donation</b>   |  |   |
| <ul style="list-style-type: none"><li>- Develop handbook of personnel and infrastructure required for establishment of living and deceased donation, including community engagement</li><li>- Develop tool kit of guidelines for minimal requirements of a deceased donor program</li></ul>   | <p>ISN, TTS, International Society of Organ Donation and Procurement, WHO Organ Donor Task Force</p>                     | <ul style="list-style-type: none"><li>- Document outlining the steps for establishment of deceased donation</li><li>- Educational tools for health practitioners and community members</li></ul>  |

CKD5, chronic kidney disease stage 5; DICG, Declaration of Istanbul Custodian Group; ESKD, end-stage kidney disease; IPNA, International Paediatric Nephrology Association; IPTA, International Paediatric Transplant Association; ISN, International Society of Nephrology; ISODP, International Society for Donation and Procurement; KRT, kidney replacement therapy; LD, living donor; ONT, Spanish Transplant Organization; ONT-WHO GODT, Spanish Transplant Organization-World Health Organization Global Observatory on Dialysis and Transplantation; TTS, The Transplant Society; TX, transplantation; WHA, World Health Assembly; WHO, World Health Organization.

Substantial initial investment is required, but this is more than offset by the lower cost of ongoing treatment and financial returns to the society as a result of improved rehabilitation. Workforce and training are discussed in theme 3, and finance issues and funding models are discussed in theme 4.

**Implement legislation for organ donation and safe transplantation in all countries.** Clear, unambiguous legislation and regulation that recognize and define brain death and address commercial transplants are the foundation of a successful organ donation and transplantation system, regardless of whether deceased organ donation is occurring or not, and need to be developed in all countries. It is essential to protect recipients and donors (from exploitation), transplant professionals, and institutions, and to eliminate organ trafficking.<sup>141</sup> Since the Madrid Resolution,<sup>141</sup> which was built on the WHO guiding principles on human cell, tissue, and organ transplantation,<sup>142</sup> the Declaration of Istanbul,<sup>143</sup> and the Council of Europe Convention on action against trafficking in human beings,<sup>144</sup> there has been an increase in the number of countries with appropriate legislation. However, in parts of Asia and Africa, this

essential component is lacking.<sup>138</sup> At present, it remains unclear how many countries lack appropriate legislation. For those with legislation there must be agreed-upon definitions of death to enable deceased organ donation. Another limiting factor in the implementation and monitoring of the effectiveness of legislation is the lack of integration of information systems between dialysis and transplant activity. The creation and utilization of registries (see theme 1) that enable linkage between use of dialysis and transplantation would allow the tracking and transparent reporting of transplant activity, providing a true denominator of ESKD and ESKD care, as well as forming the basis of a tool to identify potential living donors involved in organ trafficking.

**Integrate patient pathways that include transplantation.** Extending the detailed discussion of integrated ESKD care in theme 2, at an institutional level all patients with stage 5 CKD and ESKD should be considered as potential transplant candidates, and every unit should aspire to include a structured patient referral pathway for living and, where appropriate, deceased donor transplantation. For countries that do not have a national transplant program, the initial emphasis should be on facilitating living donor

transplantation. At a regional level there are opportunities to develop novel integrated models of care, for example, as is proposed for the East African Kidney Institute in Nairobi, Kenya.

**Promote donation.** Lack of donors remains a major challenge in both LMICs and HICs. In addition to the substantial medical infrastructure required, there are social, legal, and religious hurdles to overcome.<sup>145</sup> Even when legal requirements are satisfied, public health education and engagement with the community as well as guidance for health professionals and policy makers is essential. All countries need to develop pathways that allow potential donors to be identified in intensive care units and promote opportunities for donation after death, considering incorporation of presumed consent, which has been adopted with success in several European countries.<sup>146</sup> The need for advocacy is discussed in theme 2 and workforce training in theme 3.

#### **Theme 8: conservative care. Define the key considerations and development of conservative care as a component of integrated ESKD care**

Supportive and comprehensive conservative care are essential components of an integrated ESKD care program (Table 5). The terminology and definitions for care that optimally manage symptoms of ESKD are based on the WHO definition of palliative care,<sup>147</sup> and were agreed on at the KDIGO Controversies Conference in 2012<sup>11,148</sup> (Table 1 and Figure 6). It is imperative that comprehensive conservative care is not viewed as a low-cost alternative to the development of KRT programs in LMICs. If there are resource constraints on the availability of KRT, then management without KRT should be clearly identified as either choice-restricted or not, according to which applies.

Supportive care should be considered for all patients approaching ESKD as well as those already on KRT in all countries (Supplementary Table S4). Where high-quality KRT

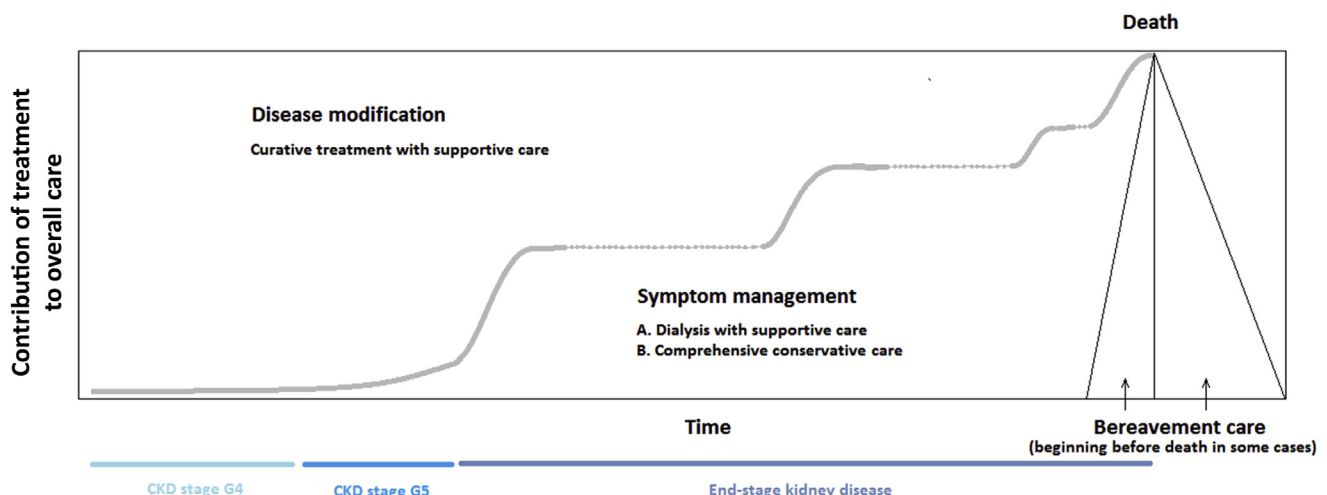
can be sustained as part of UHC, it can prolong life for the majority of people with ESKD; where it cannot, the effectiveness of partially government-funded or self-funded dialysis and kidney transplantation is likely to vary.

Even where high-quality KRT is part of a UHC scheme, for some older patients with multiple morbidities, observational evidence suggests dialysis may make little or no difference to survival or HRQoL compared with comprehensive conservative care.<sup>149–153</sup> The same applies for very young children or those with multiple morbidities.<sup>154–156</sup> Very little is known about the experiences of people with ESKD who make an informed decision for comprehensive conservative care. Even less is known about experiences in LMICs where the choice of ESKD care is restricted by KRT availability and funding; in these settings, the issue is compounded by limited availability of trained staff and essential medication to optimally manage symptoms.

ESKD was 1 of 21 conditions considered to be contributing to global avoidable serious health-related suffering in the Lancet Commission on Palliative Care and Pain Relief,<sup>157,158</sup> and its contribution will increase as populations age and the prevalence of NCD increases.<sup>159</sup> Many of the challenges outlined in the Commission are relevant to kidney disease, and some of the greatest opportunities will come from aligning the delivery of supportive care for people with ESKD, particularly those in LMICs, to the delivery of palliative care more generally (Table 12).

Activities to enhance the role of conservative care as a component of integrated ESKD care are discussed below and in Table 13.

**Generate improved information on prognosis and support for people with ESKD and their families.** Prognostic tools to support ESKD care decision-making are currently limited and require validation. These tools will require reliable, context-sensitive information on survival and self-reported people-centered outcomes such as HRQoL. The evidence base to support patients and their families is lacking, and requires the following:



**Figure 6 | An overview of the contribution of supportive and comprehensive conservative care to overall care in end-stage kidney disease.** Dashed gray lines represent a period of stability, which may be short or long. Supportive care should be offered at each stage of the disease, including information, education, relief of pain and associated symptoms, nutritional support, and social and spiritual care. CKD, chronic kidney disease.

**Table 12 | Challenges and opportunities for integrating supportive care into end-stage kidney disease care**

| Challenges   | Opportunities   |
|--|---|
| Establishing education and supply chain infrastructures for supportive care and comprehensive conservative care            | Join existing education and supply chain infrastructures established for delivery of palliative care in other conditions, using telecommunications when relevant        |
| Delivering supportive care in settings where human resources with the necessary skills are limited                         | Explore what tasks can be shifted to general physicians, nurses, physicians' assistants, other allied health professionals and community workers                        |
| Training key people to deliver effective supportive care to people with ESKD   | Training materials exist and require adapting for delivery in different settings to a range of health care professionals  |
| Recognizing comprehensive conservative care as a treatment modality without undermining support for growth of KRT programs | Clear messaging that comprehensive conservative care should be part of an integrated, people-centered ESKD service, as set out by WHO and achieved by other specialties |
| Adapting guidance and resources to the full range of settings  | Use of the ADAPTE methodology <sup>130</sup> to ensure that guidance and resources are tailored to available resources  |
| Being culturally sensitive to different attitudes regarding health care decision-making                                    | The ISN has networks with experts across a diverse range of countries and includes these experts in all activities  |

ESKD, end-stage kidney disease; KRT, kidney replacement therapy; WHO, World Health Organization.

- Careful, context-sensitive evaluation of the effectiveness and cost-effectiveness of ESKD treatment options
- Validation of tools for estimating prognosis (survival and HRQoL) utilizing national registries when available (see theme 1)
- Optimization of tools to support decision-making and advance care planning
- Development of evidence-based behavioral interventions to prevent and optimize responses to inter-current illnesses

**Make available evidence-based guidance on supportive care that is context-sensitive.** For LMICs, an essential package of supportive care resources and interventions should be agreed upon to minimize the burden of serious (kidney) health-related suffering in people with ESKD. This would guide policy makers in choosing interventions across different priorities, given trade-offs and budget constraints, and deciding how these should be financed. This guidance should help provide care to patients who might not meet local criteria for eligibility for dialysis so that such patients do not feel “abandoned” by the health care systems. It must complement and integrate with all other essential packages to enable incorporation into a universal essential health care package (see theme 2). The evidence base for the management of symptoms of ESKD needs to be developed and guidelines for symptomatic management that can be used by a range of health care workers adapted for a variety of health care settings. These would include the “essential bundle” of resources and interventions (country- and context-specific) and recognize the particular challenges of symptom management in children and young people with ESKD.

**Establish transparent, spiritually and culturally sensitive processes and metrics for monitoring equity of access to and quality of supportive and/or conservative care.** See theme 1 for discussion of definitions for conservative care and minimum

data set requirements necessary for registries. All recommendations must respect within- and between-country differences in attitudes to life, death, and medical decision-making. This includes, but is not limited to, different views held by different cultures about end-of-life decision-making. Resources need to be developed that are culturally specific, and health care professionals need to be trained to be culturally sensitive and informed (i.e., “culturally safe”; see theme 3 for discussion of training).

**Communicate clearly and effectively on the role of supportive and comprehensive conservative care in advanced stages of CKD.** The choice of terminology around conservative care can affect patient, public, professional, and policy maker perceptions and weaken messaging. Poor terminology could also make integration with established supply chains and care and education infrastructure more difficult to achieve. Supportive care must be recognized as an essential, integral component of ESKD treatment and offered to all people with advanced stages of CKD, on dialysis, with a kidney transplant, or receiving comprehensive conservative care.

**Integrate and align supportive and comprehensive care with existing renal and chronic disease supply chains and infrastructure.** The logistical challenges (e.g., availability of drugs and health professionals) and costs associated with provision of services for supportive and comprehensive conservative care need to be recognized and addressed (see also themes 2–4). Aligning terminology and ambitions with those of WHO, the World Bank, and academic commissions (such as the Lancet Commission)<sup>157,158</sup> already working to close gaps in care should facilitate kidney health to be adopted as one of their priorities. Examples of where renal services could align include the following:

- WHO's Human Resources for Health (HRH 2030)
- WHO's People Centred Care Framework
- The Lancet Commission on Palliative Care<sup>157,158</sup>



**Table 13 | Define the key considerations and role of conservative care as a component of integrated ESKD care**

| Activities   | Partners   | Deliverables   |
|--|--|--|
| <b>Improve information on prognosis and support for people with ESKD and their families</b>  |  |  |
| Undertake effectiveness and cost-effectiveness research and develop validated prognostic tools, relevant to a range of settings  | Experts in prognostic modeling, decision-making, multi-professional experts in supportive and palliative care, multi-professional experts in adult and pediatric nephrology, experts in health economics, ISN and other national and regional professional associations, patient and parent organizations, existing academic-ministry partnerships | Resource hub with tools that can be adopted or adapted by national organizations   |
| <b>Make available evidence-based guidance on supportive care that is context-sensitive</b>   |  |  |
| Adapt guidelines for supportive and conservative management of people with advanced CKD for use by range of health care workers in variety of settings   | Multi-professional experts in ESKD and supportive and palliative care, guideline writing experts such as KDIGO and ERBP  | A set of guidelines and signposting tools utilizing the ADAPTE <sup>130</sup> framework for adapting to local context                        |
| <b>Establish transparent, spiritually and culturally sensitive processes and metrics for monitoring equity and quality of care in advanced stages of CKD</b>   |  |  |
| <ul style="list-style-type: none"> <li>- Check WHO key performance indicators for palliative care and apply to supportive care where possible</li> <li>- Study role of tracking change in patient-reported outcomes over time to guide care</li> </ul>   | Local and national health service providers and funders, national renal associations, existing renal registries  | Resource hub to establish registries (see theme 1) and use data to raise awareness of the needs of people with advanced stages of CKD        |
| <b>Communicate clearly and effectively on the role of supportive and comprehensive conservative care in advanced CKD</b>   |  |  |
| <ul style="list-style-type: none"> <li>- Agree on optimal terminology for engagement</li> <li>- Develop an effective communication strategy that can be adapted to a range of settings</li> </ul>  | Experts in public relations and communication, multi-professional experts in supportive, palliative, and advance care planning, ISN and professional associations, patient and parent organizations  | An agreed terminology that works in all settings as part of a wider communication strategy   |
| <b>Integrate and align supportive and comprehensive care with existing renal and chronic disease supply chains and infrastructure</b>  |  |  |
| <ul style="list-style-type: none"> <li>- Recognize the logistical challenges and costs associated with provision of services for supportive and comprehensive conservative care</li> <li>- Understand any legal or regulatory framework for providing ESKD treatment</li> <li>- Consider opportunities from parallel models in oncology and AIDS, recognizing differences in onset and duration</li> </ul> | Local and national health service providers and funders, national renal associations, existing renal registries, ministries and policy makers, existing academic-ministry partnerships   | <ul style="list-style-type: none"> <li>- Develop costing and “business case” templates</li> <li>- Training programs (see theme 3)</li> </ul> |

CKD, chronic kidney disease; ERBP, European Renal Best Practice; ESKD, end-stage kidney disease; ISN, International Society of Nephrology; KDIGO, Kidney Disease Improving Global Outcomes; WHO, World Health Organization.

- The Lancet Non-Communicable Diseases and Injuries (NCDI) Poverty Commission (due to be published in 2018)
- The International Children’s Palliative Care Network
- The United Nations Children’s Fund

A number of charities and nongovernmental organizations have established supply chains and care and/or education infrastructures in LMICs. If renal services can partner with these, it will enhance efficiencies and prevent the development of parallel structures just for people with kidney disease. Examples of where renal services could align include the following:

- Hospice Africa ([www.hospice-africa.org.uk/](http://www.hospice-africa.org.uk/)), which is already providing palliative care for oncology, AIDS, and other noncancer end-of-life conditions
- International Association for Hospice and Palliative Care ([www.hospicecare.com](http://www.hospicecare.com)), which aims to encourage and enable each country according to its resources and conditions to develop its own model of palliative care provision
- The African Palliative Care Association ([www.africanpalliativecare.org](http://www.africanpalliativecare.org)), which aims to bring palliative care to all who need it in Africa through information, integration, and evidence

- Partners in Health ([www.pih.org](http://www.pih.org)), which is facilitating the integration of NCD services at the district hospital level in several countries, which could be leveraged to create kidney care algorithms

## Conclusions

In developing action plans to formulate a 5- to 10-year strategy to improve global access to safe, sustainable, and equitable integrated ESKD care, we involved stakeholders with broad and diverse expertise and different professional, scientific, and cultural backgrounds. The content of this document, including the action plans and performance framework, was developed in a step-wise process, involving several rounds of internal review, plenary and group discussion at the summit meeting, and subsequent working group deliberations. Despite this strength, the selection of goals and activities and their priorities remains subjective, and views about several issues are likely to differ among members of the community. Proposed activities include data capture, policy creation, definition of quality standards, evidence-based guidance, capacity-building, implementation, and research.

**Table 14 | Performance framework**

| Theme  | Area of focus  | Activities   | Measurable outputs  | Data sources  |
|--|--|--|---|---|
| 1: Estimates of ESKD burden and treatment coverage | Explain the reasons for and monitor global differences in the incidence and prevalence of ESKD, ESKD care, and modality of ESKD care | Establish and enable ESKD registries in all countries: <ul style="list-style-type: none"> <li>• Freely accessible online, mobile-enabled</li> <li>• Linked with other data sets and individual data</li> </ul>   | Inventory of CKD and ESKD registries and their data sets<br>Database reports of ESKD care resources   | Renal registries and other data sets, ISN SharE-RR committee  |
| 2: Advocacy  | Develop an approach to advocate for integrated ESKD care in LMICs  | <p>Identify and produce literature syntheses to support the development of a national kidney care program</p> <p>Develop a tool that describes and justifies the principles behind establishing a national kidney care program</p> <p>Develop and disseminate an advocacy tool kit for stakeholders' use, international in outlook but specialized by country</p> <p>Educate patients and families about CKD and ESKD and their rights and options in all aspects of treatment</p> <p>Use World Kidney Day (WKD) to highlight education and lobby governments</p> <p>Conduct consumer engagement workshops in each country</p> <p>Establish patient ESKD advisory groups in each country</p> | <p>Document library, including primary rapid reviews, systematic reviews, and economic analyses</p> <p>Scientific publication<br/>Technical report</p> <p>Key messages, infographics, economic analyses, case studies</p> <p>Established community groups with medical staff and families to drive treatment action campaign<br/>Annual WKD events</p> <p>Annual report detailing consumer engagement workshops held<br/>Register of patient ESKD advisory groups established in each country</p> | <p>Cochrane Collaboration, university-based research groups</p> <p>WHO, government officials, nephrology societies, kidney foundations, patient groups, academia and health economists</p> <p>ISN advocacy portfolio, patient and parent groups, national kidney foundations, national and regional nephrology societies, medical communities, organ donor initiatives, major industry leaders, governments</p> <p>Patient and parent organizations, ISN and other national and regional professional associations, local and national health service providers and funders, industry, governments, NGOs</p> <p>National and regional professional associations, governmental agencies (national and local), health care providers, international organizations, academic medical centers</p> |
| 3: Education and Training or Workforce             | Develop locally appropriate strategies to enhance health workforce capacity  | <p>Develop robust methodology to collect data, monitor, and make accurate projections regarding the renal workforce</p> <p>Assess training and education needs of physicians, nurses, and technicians</p> <p>Evaluate optimal methods for delivery of education and training models and impact of accreditation (included models applied by other NCDs (e.g., AIDS, oncology))</p>   | A resource hub with tools adopted or adapted by national and regional organizations, academic centers, international organizations addressing these areas with specific recommendations of how to address the local needs with information gained locally   |   |
| 4: Financing and Funding Models                    | Develop financial strategies and funding models to ensure equitable integrated ESKD care   | <p>Enunciate health care financing models of ESKD around the world</p> <p>Evaluate their impact on progressivity and equity</p> <p>Evaluate the economic and social impact of ESKD treatment including return on investment</p>  | <p>Detailed mapping of country-specific ESKD health care financing activities</p> <p>Tool to measure impact of financing models on efficiency and progressivity</p> <p>Cost-effectivity analysis tool kits developed to measure benefits to society</p> <p>Best practice recommendations for affordable treatment of medical problems in ESKD patients</p> <p>Narrative case studies showing evolution and impact of financing models developed</p>   | <p>GKHA, ESKD collection, international, regional, national societies, WHO, industry partner documents, health economic societies</p>   |

**Table 14** | (Continued)

| Theme              | Area of focus  | Activities   | Measurable outputs   | Data sources  |
|--------------------|--|--|--|---|
| 5: Ethics          | Enunciate ethical principles surrounding ESKD care   | <p>Articulate core ethical principles to guide ESKD policy and practice</p> <p>Raise awareness of ethical aspects of ESKD care among health care professionals</p> <p>Increase research and intervention guidelines in ethical issues</p>  | <p>ESKD ethics statements with other stakeholders developed</p> <p>Educational activities and resources relating to ethics of ESKD patient care including online resources developed with universities</p> <p>Established nephrology ethics leadership, mentorship and research capacity</p> <p>Publications addressing ethical issues in ESKD care in the nephrology and bioethics communities</p> <p>Strategic plan for research in the ethics of ESKD care</p>  | WHO, MSF, documents in public domain on ethical issues in health care, DICG documents, international, regional, national societies, national guidelines for ESKD care provision and rationing, global and national bioethics societies, international and national human rights organizations                     |
| 6: Dialysis        | Define, recommend, apply, and develop a monitoring framework for minimum and optimal safety and quality standards for peritoneal dialysis and hemodialysis | <p>Adaptation of existing published guidelines from HICs with focus on the applicability and flexibility necessary for lower resource countries</p> <p>Review existing documents that currently discuss standards of care from LMICs</p> <p>Consider a PD-first program after removal of structural cost barriers</p> <p>Engage national nephrology organizations, government, local partners, patients, dialysis providers, industry, academic centers and global organizations in the discussion</p> <p>Disseminate the recommendations to all health care providers involved in dialysis care, at national and regional meetings, and to local and national health care agencies</p> <p>Define safety standards for children's facilities</p> <p>Metrics for monitoring equity and quality of access to KRT</p> <p>Explore innovative approaches to ESRD care</p> | <p>Set of recommendations adapted to local settings for pre-dialysis care, dialysis initiation, dialysis frequency and dose (HD and PD), monitoring and reporting safety and outcomes, vaccination of patients and staff, infection control standards</p> <p>For HD, to include water treatment, dialyzer reuse, machine sterilization, universal precautions, recommendations for prevention of access infection</p> <p>For PD, to include infection control and monitoring, catheter placement, connection systems, and possible development of local sources of dialysate and supplies</p> <p>Application of telemedicine consultation for remote areas</p> <p>Support of new and innovative technologies</p> | Affordable Dialysis Project, Kidney Care Network, PD-first programs, hospital programs, industry, NGOs, PPP, KDIGO, KDOQI, various international guidelines, governmental health care agencies, international organizations, (ISN, IPNA, ISPD) academic centers, dialysis providers                               |
| 7: Transplantation | Define the key considerations for expansion of kidney transplantation as a component of integrated ESKD care   | <p>Extend implementation of legislation to all countries</p> <p>Enable tracking of dialysis and transplantation activity</p> <p>Develop region-specific attainable targets of transplant activity, and how this might be affected by regional transplant networks</p> <p>Promote deceased organ donation (DOD)</p>   | <p>Accurate inventory of countries lacking legislation</p> <p>An integrated database of dialysis and transplant activity</p> <p>A guide to appropriate levels of transplantation to support growth</p> <p>A guide and set of tools that outline the steps required to establish DOD</p>  | <p>International registries and GKHA</p> <p>Integration of existing dialysis and transplant registries</p> <p>Cost-economic models of the investment or payback based on LMICs data</p> <p>Reported experience and barriers and resource requirements from existing programs and LMICs that have achieved DOD</p> |

(Continued on next page)

**Table 14** | (Continued)

| Theme                | Area of focus   | Activities   | Measurable outputs   | Data sources   |
|----------------------|---|--|--|--|
| 8: Conservative care | Define the key considerations and development of conservative care as a component of integrated ESKD care | Information on prognosis and support for ESKD<br>Context-sensitive guidance for supportive care<br>Metrics for monitoring equity and quality of conservative care<br>Agreed terminology that underpins communication<br>Alignment of care with existing chronic disease infrastructure | A validated prognostic tool for dialysis and conservative care outcomes<br>Guidelines that can be adapted for different resource settings<br>Key performance indicators for conservative care<br>Published terminology<br>Collaborative partnerships to be developed and functioning | International registries capturing key metrics<br>Multi-professional experts, patients and carers<br>WHO performance indicators for palliative care, expert opinion from renal and chronic disease groups<br>Sharing of knowledge, training and infrastructure |

CKD, chronic kidney disease; DICG, Declaration of Istanbul Custodian Group; ESKD, end-stage kidney disease; GKHA, Global Kidney Health Atlas; HD, hemodialysis; HICs, high-income countries; IPNA, International Paediatric Nephrology Association; ISN, International Society of Nephrology; ISPD, International Society for Peritoneal Dialysis; KDIGO, Kidney Disease: Improving Global Outcomes; KDOQI, Kidney Disease Outcomes Quality Initiative; KRT, kidney replacement therapy; LMICs, lower-middle-income countries; MSF, Médecins Sans Frontières; NCDs, noncommunicable diseases; NGOs, nongovernment organizations; PD, peritoneal dialysis; PPP, private-public partnerships; SharE-RR, sharing expertise to support the setup of renal registries; WHO, World Health Organization.

Partners in these endeavors will include patients, governmental agencies, policy makers, academic institutions, health care institutions, industry partners, research funding agencies, clinicians, and researchers.

After identification of existing gaps in knowledge, clinical practice, and access to ESKD care around the globe, action plans were developed to improve monitoring of ESKD and its therapeutic options; to advocate for expanded and equitable ESKD care appropriate to the context of local resources, health priorities and culture; to build capacity by training a diverse workforce; to define standards for safe, sustainable, and ethical ESKD care; and to establish dialysis, transplantation, and comprehensive conservative care as complementary treatment choices for patients with ESKD. These plans and associated activities will need to be adapted to the needs of individual countries, based on geographical, socioeconomic, cultural, and political considerations. Finally, the participants reiterated the need to embed improved ESKD care in the overall environment that prioritizes prevention and early treatment of kidney diseases.

Granularity within each of the activities and deliverables will be developed over the coming months in conjunction with various partners identified in the action plans, and with those partners a detailed strategic plan defined for implementation over the next 5 to 10 years. A performance measurement framework will be developed for qualitative and quantitative assessment of progress in implementation of each component of the strategy, and to hold the nephrology community and other stakeholders to account. The performance framework is presented here at a high level (Table 14), and will be fleshed out as the strategic plan is finalized. We perceive a broad recognition among all those involved in the care of kidney patients of the importance of improving global access to safe and sustainable integrated ESKD care, and that the inclusive involvement of all relevant individuals and groups in implementation and tracking of progress will lead to improved care and outcomes for patients with ESKD globally.

## APPENDIX

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The views expressed in this commentary are solely the responsibility of the authors and they do not necessarily reflect the views, decisions, or policies of the institutions with which they are affiliated.

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PGB reports personal fees from Ontario Renal Network. F Hou reports personal fees from Astellas, AbbVie, and AstraZeneca outside the submitted work. RTK reports personal fees from Baxter outside the submitted work. JP reports grants and personal fees from Baxter Healthcare, Fresenius Medical Care, and Davita Healthcare partner, outside the submitted work. VT reports relationships with Amgen, Baxter, Bayer, Boehringer-Ingelheim, Chemocentryx, Fresenius Medical Care for consultation, and member of their advisory or scientific board. RW reports grants from Baxter Health Care outside the submitted work. QY reports personal fees from Baxter Healthcare outside the submitted work. XY reports grants from Baxter Health Care, Wangbang, South Pharmaceutical Group outside the submitted work. All the other authors declared no competing interests.

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## AUTHOR CONTRIBUTIONS

DCHH, SJD, FOF, and VJ were responsible for conception, organization, writing, editing, and reviewing the manuscript. JD was responsible for organization, editing, revision, and logistic organization, including reference management. All other authors were responsible for initial drafts of specific sections of the manuscript, review, and validation after each review.

## SUPPLEMENTARY MATERIAL

**Table S1. (A)** Prevalence (PMP) rates of end-stage kidney disease (ESKD) (treated), dialysis, hemodialysis, peritoneal dialysis, kidney transplantation, and donor type comparison across all 4 World Bank country classification groups (HIC, UMIC, LMIC, LIC). **(B)** Incidence (PMP) rates of ESKD (treated), dialysis, hemodialysis, peritoneal dialysis, kidney transplantation, and donor type comparison across all 4 World Bank Country classification groups (HIC, UMIC, LMIC, LIC).

**Table S2.** Data sources by country, International Society of Nephrology (ISN) region, World Bank income classification, and year.

**Table S3.** International Society of Nephrology (ISN) fellowship program statistics. Number of renal fellows sponsored by the ISN by home and host region.

**Table S4.** Framework for considering supportive care for high-income countries and low- and lower-middle-income countries.

Supplementary material is linked to the online version of the paper at [www.kidney-international.org](http://www.kidney-international.org).

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